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**family carers of adults with
severe mental illness:
conceptualising carer experience and need.**

**a thesis submitted for the award of Ph.D of the University of Durham
Department of sociology and social policy.**

June Wainwright June 1997.

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23 JAN 1998

abstract

This study explores the experiences of people caring for, or supporting, relatives described as suffering severe mental illness. For the purposes of the research this has been defined as schizophrenia or bipolar disorder (manic depression). Qualitative method has been used to emphasise the powerful nature of the experiences that the subjects encountered. The study has innovatively used the researcher's own caring career which unfolded during her period of study registration. The difficulties and advantages of this approach have been examined within a feminist framework.

The research also explores the experiences of a small number of carers of people with dementia as an aid to highlighting the particular needs of those supporting people with severe mental illhealth. The data is presented in terms of the carer's path through the mental health system. It traces the cyclical periods of despondency and hope that accompany the service user's symptoms.

Since the implementation of the NHS and Community Care Act 1990 family supporters of sick and disabled members have been afforded recognition as *carers*. Their often tireless provision of assistance, and their cooperation with statutory services are essential to the success of the policy of non-institutional care. *Community Care* has been put forward as the ideal for a whole range of service user groups, many of which were previously catered for in large hospitals. While it would appear prudent for the state to support people who perform this difficult and demanding task, at no cost to the tax payer, the study shows that carers' practical and emotional needs continue to be inadequately addressed. The experience of carers is conceptualised as *attachment violation*. Discussion explores the destructive dimension of severe mental illness which attacks people's relationships, cutting both users and carers off from support at a time when it is most needed. Carers found themselves dealing with distressing changes in their relative's behaviour, which might lead to the user and others being placed at risk. Despite this, carers' attempts to seek help from outside were often rebuffed. The study concludes that major changes are needed in the way that mental health professionals relate to people who find themselves trying to secure support for relatives who appear unable to do this for themselves.

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Introduction

This research is the product of five years part time study, and was funded by the ESRC. It is intended as an attempt to highlight the experience of carers, to re-examine the ways in which they have been perceived, and to develop theory which might inform better practice.

In the first chapter I will locate the research explaining its conception, the ways in which I have used professional, personal and academic strands of experience to inform the investigation, and to enhance access. The discussion and subsequent method can be unconventional, but it employs a rigorous commitment to critical self-examination. The use of personal material, as well as data collected within the confines of the 'interview' allows the study to exploit a wealth of data that would have been largely inaccessible. In the second chapter the carer's story is placed in its current legislative context. The new rights and assistance promised to carers are examined critically.

The third chapter reviews the literature concerning severe mental illness, in particular its two commonly recognized forms, schizophrenia and bipolar disorder. The discussion is predominantly medical. The experience of people with severe mental illness is constructed and administered through the language of psychopathology. People become patients, they have diagnoses, prognoses, and treatment plans. Their lives are constructed as illness, but it may not even be an illness that they themselves acknowledge. Radical literature is also reviewed. Anti-psychiatry theory criticises the medical approach, and sociological theory lays bare the psychiatric industry with its poorly veiled power interests, but they do little for carers, in fact they have arguably disempowered carers further. This literature is presented in terms of its influence in shaping public and professional attitudes towards family carers.

In the third chapter there is an examination of the research concerning carers, and in particular an attempt to explore the ways in which carers in mental health can be perceived as being *real* carers. Comparisons are attempted with other groups such as older people, those with a physical disability, and the learning disabled. It appears that family supporters of mentally ill people have rarely been thought of as carers but were more often suspected of playing a role in actually causing their relative's mental health problem. The research examines the barriers to the recognition of carers by the public, by their relative, and by carers themselves. It then traces the ways in which experiences come to be constructed as problematic and eventually as mental illness.

At all stages the research focusses on the carer, and on their feelings, problems, and needs. The research does not seek to minimise the disempowering experience of service users but attempts to record and examine the views of a group who have been marginalised and

exploited. Material drawn from carers of people with dementia is used as an aid in comparison, such carers being more readily accepted by professionals as being legitimate carers.

The experiences of carers are portrayed as a story or journey through the system. In this sense I refer to the psychiatric system through which users and by default their carers are processed. The system becomes an unavoidable aspect of their lives, it is resented, tolerated, hated and feared. Carers may try to escape it, but those excluded from the system often felt utterly abandoned, and were exposed to all the vicissitudes of severe mental illness.

The events portrayed in the 'carer's story' rarely had any clear beginning, middle, or end, but might show cycles where events repeated themselves over and over again. The research attempts to relate the flavour of these experiences using a qualitative approach. It describes and analyses the roles played by key professionals in the carer's encounter with the system and demonstrates how the illness, for want of a better term, impacts on their relationship with the relative and throughout their whole life.

An examination of the experiences of self-harm and aggression by users is provided in the latter part of the exploration of carers' experiences. Although isolated acts of violence are most often foremost in the minds of politicians and the media, coping with self-harm and, on occasions, disturbed behaviour is a regular experience for many carers. Just when the carer feels they have endured everything, seen all there is to see, and fathomed the depths of despair, they will often have to face yet another expression of desperation by the relative. The research seeks in particular to express the relentless course of the illness and rather inadequate ad hoc responses offered by the system.

The final chapter returns to the themes that carers face, their turmoil, isolation, and the appropriateness of loss theory to their experiences. I conclude with some discussions of carers' main needs and of how these might be met.

I would like to thank everyone who has supported this research, and in particular the people who have shared their experiences with me. This must include my partner who has had the courage to allow me to tell our story.

Somewhere between melodramatic ruthless exhibitionism and a long suffering hypocritical secrecy there may be a way to write this thesis. Layer upon layer of introspection, there may be a middle way between unquestioningly presenting the 'truth' and asking that the reader bow to my ethnographic authority, or fearing to have the courage to tell our story because I have considered my role in interpreting the 'facts' so intensely that I have lost my voice.

I am not writing this paper as a catharsis, though it may have that end. It is written in the hope of promoting change in practice and to develop understanding- emotional and conceptual.

Chapter One

The Research, its Rationale, Problematic and Method

Research is never carried out in a cultural vacuum. It represents the carefully contrived fruits of a process of academic interest, prior knowledge, time, and the approval of funders or employers. Bryman (1988) notes that reality is “messy” (1988:21) and does not easily succumb to slick research procedures that might contrive to deny this. Recognising that this research inevitably offers a particular representation of the experience of families supporting a relative suffering severe mental disorder, it will attempt to locate itself opaquely. In short it exposes its strengths and weaknesses for inspection.

The subject of the research arose from day-to-day contact with families supporting people experiencing severe mental illness. Working as an Approved Social Worker under the Mental Health Act I was frequently in contact with families during crisis and involved in the patient’s admission. I was also part of a multi-disciplinary mental health team offering long term support (this often covered a period of years rather than weeks). As a mental health worker I entered into enduring relationships with families. Although some people recover and leave professional support behind, for many people with severe mental illness there will be a long relationship with the psychiatric system.

This thesis was written during the period between 1994 and 1996. It reflects the changes in my perception and understanding that occurred, as in Warren’s terms the thesis was written and re-written (Warren, unpublished). As I moved from being a field mental health worker, to being a carer of someone with a

severe mental illness, to working as a social work academic (far removed in my 'cardboard' intellectual tower) and then all three, so my perception changed. In short I have been able to conduct research from a range of roles, and I have tried to use this multi perspective approach to add richness to the quality of the data. Although distance from the subject may be perceived as advantageous, and even essential for developing objectivity, I found that I was paralysed when removed from the field. The thesis has depended on the interaction of professional practice, personal experience, prolonged contact with users and their families, *and* the application of analytical skills derived from qualitative research methods. Approaching research in this way has meant that I have lived and worked the subject virtually 24 hours per day.

Stanley (1991) has drawn attention to the patriarchal system of production that exists in so much academic research. A similar division of labour exists in social work, where the successful are frequently expected to distance themselves from hands on work. Management and policy are conducted at a distance from service provision. Men manage and think, women act as field workers and are often the carers this study discusses.

Research carried out by those based in academic institutions is not always driven by the quest for wisdom. Even an academic will be subject to the pressure of funders, with their agenda (Platt, 1976). Research conducted with the backing of public research funding must pass through the hoops of intellectual respectability, and this must exert control over the topics studied and the methodology used.

Everitt et al recognise that "good practice, research and theorising are interdependent" (Everitt et al, 1992) and that research carried out by practitioners is likely to be closely linked to the mechanisms of practice. However, it also follows that steeped in the alleged realities of the subject matter, practitioners might be unaware of wider issues, or of the conceptual strait-jacket of their professional paradigm. As a practitioner, a teacher, a woman and a carer the concept of research, that is not immersed in exposure

to the field seems unviable. On reading many psychiatric, psychological and sociological texts I have come to believe that one can not begin to appreciate the experience of mental suffering, and of the impact it can make on family life. This research will attempt to bridge that gap, linking feelings, experience and theory.

It is wise to be wary of claiming something akin to ethnographic authority, ie that *I know* how things are experienced. This work provides just one account of the experiences of relatives caring for mentally ill people and is constructed from a particular vantage point. However, the material I gathered (beyond the single, snap shot interviews), possesses depth and this would not have been reflected in an approach based around formal interviews alone. Living the data as a carer I was rudely introduced to the ways in which mental ill health influenced all areas of life. I was also aware of the difficulties that I encountered in relating these experiences to professionals in a way that satisfied me that they comprehended my experiences.

In this thesis I define severe functional mental illness as schizophrenia and manic depression (bipolar disorder). They have traditionally been considered *functional*, as the nature of any underlying physical pathology remains undemonstrated. This does not mean that there is none (Gelder et al, 1993). These two diagnostic categories are frequently associated with periods of severe symptoms, disturbed behaviour and chronic disability. The nature of these disorders, and the way in which they have been used in the study, will be discussed more fully in Chapter 2.

Role Confusion or Triangulation: My Involvement in the Study

In order to interpret the data it is vital to locate my role in its development because research is not a neutral process. Writing in October 1994 I noted that my references to a multiplicity of roles was inexplicit. Three months later I attributed this vagueness to an uneasiness with my experiences as a carer. As I write, I try to peel away the layers of discovery, and reveal a spiral of

understandings. Warren (unpublished) noted the process of writing, editing and rewriting. At what point is the story ever complete? The search for an *answer* reveals a lingering vestige of positivism. The thesis cannot do justice to the dynamic processes involved.

I was encouraged by my study supervisor “to make regular notes and to reflect on the data”. This procedure is endorsed by Glaser and Strauss (1968) and Strauss and Corbin (1990), who advocate writing memos to one’s self about emerging themes. A pattern gradually emerged from my research diary, and I became conscious that **“I was sitting on a minefield of autobiographical material”**.

References to my ‘difficulties’ were initially inexplicit, or recognisable by complete gaps in my diary. There were periods of time when I could not work at all and had been too depressed, exhausted, or traumatised to describe these events to anyone or reflect on their nature. I regarded them as quite separate from my professional sphere of life. With hindsight I can acknowledge that I was engaged in the early phases of addressing and conceptualising particular difficulties or behaviour by my partner. His periods of sadness, aggression and emotional outbursts might have been recognised as indicative of severe mental illness, though they could also be viewed as volatility. Refusal to acknowledge the threat posed by such experiences can be viewed as denial, or more simply as a survival strategy (if I did not write it down, it had not happened). I came to acknowledge my ‘position’ as a carer, and its consequences, through a process trodden by many others whose stories are used in this study. The making of a ‘carer’ in this context is the product of a number of complex processes and the would be carer must ‘successfully’ complete each one. I took my place in the study group because I was processed through these stages, and stand as a fully authenticated carer recognised through my partner’s diagnosis. Whether or not I am fortunate in this is debatable but there are others in the current study excluded from this role although their needs and experiences do not differ significantly from those recognised by the services. In order to explore

the processes involved through which carers are constructed and related to by the public and by professionals I have drawn on material from subjects who fall outside of the criteria used by the mental health services.

People frequently study a field where they possess prior understanding (Hobbs, 1993). It seems quite reasonable to commit time and energy to a subject where one has emotional investment. On a more cynical basis, it can ease access considerably (Ruane, unpublished, experienced significant difficulties obtaining access, in the field of adoption research. This may have been associated with her status as an outsider, in relation to social services). Prior to my development as a carer I did possess some understanding of mental ill health.

I came to the research as a social worker who was passionately committed to working with the severely mentally ill. Completing training in 1989 with that goal in mind, I practised as an approved social worker. I had a personal history of depression, anxiety, and a brief encounter with an eating disorder. At 22, I had been referred to a psychiatrist as an out-patient, but though my problems were enduring and had caused me unhappiness, I would not feel entitled to call myself a *user of mental health services*. My partner of eight years had also experienced problems throughout his life. I was aware that at times these had been rather more severe than my own, and that he had been in hospital for a month. Despite spasmodic, unproductive referrals to psychiatrists, Community Psychiatric Nurses and to a psychologist, he avoided medication and coped with his disorder. It did not have a firm diagnosis but at times had been called: "psychotic depression", "depression", and "anxiety". We were not part of the psychiatric system and our emotions, careers, finances and social lives were largely intact.

In October 1993 my partner lost his part-time teaching job and entered a period of depression. Although he had often expressed suicidal ideas before, I had developed a strategy of non-intervention. However, one day in November I received a phone call at work - he was battling with an over-powering urge to

hang himself, and felt that he was losing. I decided to do what I would have done for anyone else and fight for his life. This was the point at which we entered the psychiatric system. I assumed the role of carer with all that it entailed. I now feel comfortable with the term, as in Twigg's usage my life is 'significantly disrupted' by caring (Twigg and Atkin, 1994).

People like to know what you are, and I presented a problem. Some professionals admitted to feeling uncomfortable about our problems and regular appearances at 'client' resources. Although the social work profession pays lip service to the idea that anyone can have severe mental illness, the patient population are largely an underclass poor, tatty dressed and bearing the stigmata of the side effects of medication. The illnesses take a sad toll on people's social skills, motivation and relationships. I used my technical knowledge to counsel, support and assess risk. I do not believe that any carer would do differently. Although I was frequently asked by professionals, to "just be his wife", I could not separate the roles for the convenience of others. Community care policy asks that relatives and friends assume the "key worker" role, if this be the case, professionals must transform their relationships with carers, to reflect this development (see Twigg and Atkin, 1994 for a discussion of the ways in which professionals regard carers).

The alleged role conflict also created problems for me in obtaining support. I turned to other carers who I had met through the research and phoned them in desperation. I referred myself to social services and was formally allocated to a colleague. Initially threatened by the responsibility, she became a life line for my partner and I.

In becoming active in user and carer affairs I have been readily accepted by other carers, once I explained my position. Initially afraid to usurp this role and deny *real* carers the opportunity, I now assume it with an acceptance it is my right.

There is, was, always the hope that the problem would be short-lived and that I would return to a single professional identity - this has not been the case to date.

The Emergence of Grounded Theory

Glaser and Strauss have been particularly influential in the area of qualitative methodology. In their approach the incipient ideas for the research 'emerge' from the data, and are not imposed upon it. They rejected methodology where theorists constructed theory in isolation from the subject matter and advocated the production of "grounded theory" (Glaser and Strauss, 1968). Although their distinction has been helpful in highlighting the value of creating theory through empirical exploration, it may neglect the involvement of the researcher. This research grew through an interaction with the families I encountered in my work as a mental health social worker but is also the product of my many roles. In some sense I have responded to Denzin's call for triangulation by working as mental health worker, research student, social work academic and as a carer (Denzin, 1970).

I would suggest that theory is neither purely imposed on the subject matter, nor does it simply emerge from the data. We are constrained in our observation by the culturally moulded paradigms in which we have been schooled. We can not screen out our previous experience and encounter social phenomena as anthropological "virgins". The strength of Glaser and Strauss' approach lies in its emphasis on exposure to the field, which they advocate is less likely to lead to erroneous theory, divorced from empirical experience (Glaser and Strauss, 1968). However we should not attempt to deny the wealth of knowledge that we can bring to research. Although the cultural stranger may be able to draw attention to the "taken for granted" aspects of social life, someone sensitised to an area of experience is well placed to understand, and reflect on, the subtleties of that field. It was from the latter position that my understanding developed, through constant day-by-day exposure and reflection. Thus the 30 or so formal interviews that I conducted represent a small part of the "fieldwork" that has surrounded this project. Formal interviews were interwoven by on-

going contact with carers, by attendance at self help groups, involvement in the development of a user/carer forum, discussion with professionals, informal contact with people who have severe mental health problems, more recently involvement as a carer member of the management of a mental health charity and at present 3 years' intense experience of caring at home.

In attending seminars I have heard it suggested that the research project is shaped and constrained by the practicalities of funding duration, or the period of registration and study required for the degree. I chose the subject because it stimulated me intellectually, because on a human level I could see that there was work to be done, and pragmatically as I felt that I was unlikely to find access a difficulty. I did not anticipate the power of the experiences to dominate me - experiences that formed the topic of the research possessed the power to subjugate all aspects of my life. I have come to see myself primarily as a carer, and regard my other roles as peripheral.

Caring, an Experience of Loss?

As a mental health worker I was regularly in contact with people experiencing the acute stages, and lengthy aftermath of severe mental illness. Often such individuals had been in psychiatric hospital, and then faced the long slow road towards recovery. In some cases this might be a complete recovery with a return to employment or a former role, but more frequently the recovery was partial, and there would be a tendency to relapse. Leonard Stein at the Mental Health Matters conference (June 1994), drew attention to the stages that characterise both physical and mental disorder. The initial period is one where the individual's system can be described as "out of control". In psychiatric 'illness' this period may be characterised by strange ideas, disturbed behaviour, aggression, or auditory hallucinations. With medication this period can usually be brought quickly under control. However, the acute stage, where the patient might be cared for in hospital, is frequently followed by a prolonged period where, though no longer acutely ill, the patient suffers impairment in their functioning. The term mental disability does not therefore seem

inappropriate. It is frequently at this time that the patient and their family will begin to consider the long term reality of the illness, as the hope of a return to full health fades. It was through contact with a family confronted by these issues that I first became impressed by the sense of loss they faced. Working from this point, I began to consider investigating the appropriateness of the concept of loss as a model for understanding the experience of relatives. In this sense the research was indeed 'grounded'.

Dementia Sufferers and Loss

Glaser and Strauss (1968) discuss the wisdom of using contrasting groups to highlight insalient features of data. At times aspects of the familiar evade recognition, and examination of situations that are strikingly different to the study area can raise one's conceptual sensitivity. I decided to use the experience of people caring for victims of dementia (for example Alzheimer's disease) as a contrasting group. Common sense notions suggested that if caring for a relative experiencing severe mental illness could be understood in terms of loss, then this would apply readily to the situation of dementia carers. This illness is associated with the erosion of personality, intellect, and physical capability. Its course is progressive leading to death (Pitt, 1982).

Much has already been written about the carers of dementia sufferers and at times the term "living bereavement" has been used. Gilliard (1992) questions the suitability of such expressions, arguing that an analogy with bereavement can exclude the positive aspects of caring. It seemed that a contrast between carers of people with Alzheimer's and those with schizophrenia or manic depression might fruitfully illustrate the extent to which the "loss" concept might be applicable as the basis of a theoretical model. There was also a need to ground the theory. It might be argued, for example, that the experience of a wide spectrum of families could be understood through the concept of loss. Caring is also a feature of "normal" life and at times the physical and emotional burden on any "carers" might be intense. Why should the lives of people

supporting the severely mentally ill be conceptualised separately and specialist services provided?

The Choice of Qualitative Methodology

As the study progressed it seemed that in academic circles at least qualitative methodology had acquired respectability (the support of ESRC funding demonstrates this development).

The practicalities of doing small scale research made it unlikely that I would be able to handle large numbers of respondents and treat the data to statistical analysis. I sought an approach that could remain flexible to emerging themes, and would not pre-conceptualise respondents' experience, (acknowledging that all interactions must involve a degree of such conceptual constraint!), through a range of closed questions or validated 'instruments'. Some research concerning the experience of carers has relied heavily on such interview schedules. Eagles et al (1987:294) used the General Health Questionnaire to determine whether carers of older people could be regarded as distressed or depressed. Making such distinctions can create a false sense of security. They may lead service providers and professionals to believe that they understand carers' experiences and hamper innovative responses. Eagles et al (1987) suggested that the distinction between depression and distress in carers indicated whether they could be helped by social workers, or whether they needed psychiatric intervention. Presented with a 'clinical depression' it is too easy to ignore the context in which it was generated, and to respond to the carer in isolation, treating *them* as mentally ill.

Conversations with carers have suggested that distinctions drawn by professionals, may appear relevant to them alone. To the struggling families professional boundaries or attempts to medicalise their distress can appear frustrating, bewildering, and at times patronising. Resenting the danger of

'patientising' carers, I wished to employ a methodology that could reflect their own categories of experience. As far as possible, I wanted to remain sensitive, able to 'hear' people accurately when the information they gave me was unexpected, or apparently paradoxical. It therefore would have been inappropriate to assess carers with instruments that would detect their needs as defined by the dominant professional groups.

Everitt et al (1992) noted that quantitative methodology which could be characterised by large surveys, where the resultant data was subjected to computer analysis, had often fallen into the trap of treating the collection of *facts* as unproblematic. Somehow the tables of figures acquire persuasiveness. Such (specious) sophistication is allegedly lacking from the soft data or 'stories' produced by qualitative studies. The carers' study grew in the power context of medical dominance, and with the associated supremacy of *real scientific investigation*, epitomised by the double blind clinical trial. Much of the research with which my medical contemporaries are acquainted has involved the large scale testing of drugs, therapeutic regimes, etc. Success being established through demonstrating a range of indicators of improvement. Such are the marks of respectable science.

The approach that I chose reflected the complexities of the subject and an acknowledgement that in Bryman's sense, data is constructed (1988). Such methodology could cope with any 'messiness' and with my role in the research process. Moreover Corbin and Strauss (1988) have drawn attention to the value of qualitative methodology in researching human *experience* (their study examines the experience of caring for sick relatives). In order to reflect respondents more fully, it can be important to represent them in their own words. The 'richness' of the data resists reduction to numerical representations of variables far removed from the lives of the subjects.

Feminism and the Legitimation of Involvement

Feminists have drawn attention to the need to examine the experience of women, and to creating theory that acknowledges that women's experiences may differ from those of men. Spender notes that mainstream theory reflected a gender-blind view of society. She struggled for the conceptual space to think about men's theories, 'wondering how to move outside them: they occupy all the conceptual space, noting the looks of surprise and confusion at the suggestion that their logic, their truth, their reasons and their theories are but one version' (Spender, 1983:30).

It felt vital to incorporate a feminist perspective as the work on carers covered territory all too familiar to women, that of the daily grind of supporting family members both physically and emotionally. Walker's work had drawn attention to the reality that caring is usually the prerogative of a single female relative (Walker, 1983). Such a perspective does not negate the commitment of large numbers of men who also support family with mental health problems, but feminist literature has enhanced academic understanding of roles so often carried out by women.

Feminists have made a significant contribution to the process of legitimising the use of qualitative analysis, and to the examination of power issues in the research process. Given that many of the users of social work services experience multiple disadvantage it was ethical to seek ways that would reduce the potential for exploitation and involve the research subjects as much as possible. This process was paralleled by the impact of the NHS and Community Care Act 1990 that requires consultation with service users and carers at an individual and service planning level.

The work of Oakley was seminal in the debate about researcher involvement with subjects. It was conducted at a time when survey research was carried out within a value neutral framework. The researcher was trained to be invisible, lacking as far as possible personal views, and other characteristics that might

contaminate the 'purity' of the data. Hence, attempts by the interviewee to engage the researcher in conversation were to be rebuffed. Oakley found this position untenable, and began to resist its implications from a feminist standpoint. Researching women and their experiences of childbirth she found that she was unavoidably drawn into the lives of people she met. She frequently had to make several visits, drink tea, and in some cases became a personal friend. The women shared their views but also sought her experiences. She stopped trying to resist these developments and legitimised them as part of the dynamics of the research process (Oakley, 1981).

Finch continued in this vein and noted the willingness with which women would share their experiences with other women. Although this was positive in the light that it demonstrated the rapport that might quickly emerge between women, it also demonstrated the vulnerability of women to exploitation in the research process (Finch, 1984). As women have tended to stay at home and care for the children, George Brown and colleagues acknowledged taking active advantage of this situation, and interviewed only women in their study of depression in the community (Brown and Harris, 1984). Obtaining access is a basic obstacle in any research and one might be tempted to research vulnerable groups. It could be argued that those of lower socio-economic status, or people isolated by the burden of mental illness, could be easy prey. Such individuals might welcome the opportunity to unburden themselves to a sympathetic stranger. It felt important for this project to remain conscious of the potential for exploitation. My role as a carer made this an even greater risk because access was facilitated further.

The experience of feminist researchers provided a theoretical framework for my own social work practice. I had developed a professional style that frequently entailed the development of close relationships. In sharing their innermost thoughts, doubts and, day-to-day struggles, clients often sought an understanding of my own views and social situation. I visited many families regularly over a period of several years. They built up a picture of my homelife and background. As I shared their tea, distress, and successes, I believe

mutual relationships developed. The traditional therapeutic relationship involves warmth (Egan, 1990), but also professional expertise (power?) and social distance. The therapist is encouraged to achieve a close relationship with the client, but traditionally this relationship lacks reciprocity. The personal qualities and experiences of the therapists are to be kept veiled, unless the professional engages in self disclosure (this should be limited and deliberate). The relationship exists only to address the needs of the client. I suspect the reality of practice is a little less tidy. The art of using the self must remain an ideal, rarely achieved. I think it probable that where involvement is long term, and where much of the contact occurs in the informal environment of the client's home, there will be an increased likelihood of reciprocity in the relationship. I believe that the traditional model for client-worker relationships reflects not only the goal to devoting one's self entirely to the client's needs, but also reflects power structures. It can feel very safe to retreat behind a facade of wisdom, denying the universality of human vulnerability. The latter stance really serves the needs of the therapist, despite professional self deception.

Greed noted that it was less easy to apply 'hit and run' tactics in research when the relationship was long term or when one was researching a setting to which one actually belonged (Greed, 1990). In carrying out research over a period of time, the researcher who evades attempts by the interviewee to involve her in the discussion may expose herself as lacking substance and as an unworthy confidante.

'Traditional' research, seeking scientific sanction, may simply have sought to bowdlerise the untidy aspects of research with human subjects. Kelly notes a process of 'sanitisation' (Kelly, 1988).

We must also look between the spoken lines as Devault (1990) has drawn attention to the ways in which language alone may not convey the understandings that women can share. Hence the researcher must also make reference to the grunts, moans, and emotional atmosphere of the interviews. Such additional inconvenient aspects of the data make its reduction to

categories and statistics almost impossible. I could not do justice to the stories of the subjects without acknowledging their expressions, silences, and those feelings that they recognised but said they could not verbalise.

Meeting the challenge of reflecting the richness of social life is clearly difficult. Tidy accounts deny the way in which researcher and subject construct the interview together. Roseneil notes that Finch describes the process of research interviewing as 'dialogic' (Roseneil, 1993:198-199).

It could be argued that conducting research and social work within a 'collaborative' (Finch, 1984) framework the resultant product would be a highly subjective account, lacking in wider relevance and generalisability. I would suggest that its strength is in an ability to link personal experience to sociological problems (see C W Mills' account, 1979). Mills notes that when personal misfortune is replayed again and again it begs sociological analysis. The term subjective has become a misnomer for sloppy, emotional, and unscientific. It should be logically possible to seek both rigour and subjectivity. Like it or not emotion, feeling and individual experience are part of human reality. Rather than deny them or banish their presence through doctoring up our professional language we should be prepared to study them openly. It would have been impossible for me to explore carers' experiences without an appreciation of these aspects. A 'collaborative' approach to data collection permitted me to draw out and explore people's emotions, as they appeared to lack the vocabulary to articulate their feelings. Given the lack of recognition that this area of experience has received, it is probably not surprising that carers experienced difficulty in relating the enormity of what had happened to them.

Feminist thought has been instrumental in legitimising the examination of personal experiences. It has 'insisted that personal experiences couldn't be invalidated or rejected, because if something was felt then it was felt, and if it was felt then it was absolutely real for the woman feeling and experiencing it'

(Stanley and Wise, 1984:53). It has challenged the ways in which social life can be represented through an academic medium.

Patriarchal dominance of the boundaries of academia ridiculed the status of feelings and personal experience.

The traditional male emphasis has been on objectifying experiences and so “getting away from” the personal into the transcendental realm of “knowledge” and “truth”. For feminists the key consequence of this is that it denies validity to women’s understandings of women’s experiences, because these are “merely” subjective, rooted in the particular. It also, of course, denies validity to the realms of emotion and physicality more generally, instead arguing that “rationality” and “mind” are superior to these. (Stanley and Wise, 1984:53.)

While what may be regarded as the epidemiological style of research has many advantages, there are also benefits to looking in depth at the experience of the individual. Smith, in Farran (1987) observes the way in which in which sociology has been the study of social groups. However, in looking at categories that can be generalised throughout the group the meaningful characteristics of personal experience may be sacrificed. The ensuing sociological description may consequently be bland and able to contribute little to understanding the complexities of people’s lives. Hence, through adopting a case study approach, there is an attempt to increase the reader’s ability to understand how mental illness impacts on the individual person disrupting their ability to find meaning in their existence.

Rubin, in 1976, noted the problems of researching small numbers of subjects and how presenting the experiences of such subjects might be attacked for being biased and colloquial by the then sociological main stream. Working in the area of pain, she talked to a small group of working class people. Her sample was not selected at random and, coming from a working class background, it might be alleged that the study was flawed. Her findings were

presented in a 'story like' way (Bowles, 1983:37). However, recognition that the experiences of women are different from those of men has started a process that has legitimised the presentation of academic material in new ways. Ways that acknowledge patriarchal language can not convey women's experience adequately. With this in mind I realised that it did not feel comfortable or helpful to write in an impersonal way. Also a rejection of the 'first person' can be regarded as a literary guise adopted to enhance academic credibility (see Hammersley, 1992). An allegation of bias is inevitable but I will attempt to make the sources of such bias visible and available to examination. Roberts quotes Becker, who notes that allegations of bias do not relate solely to methodological procedures which could be rectified through a process of refinement but suggests that 'the sociologist provokes the charge of bias whenever he says something that denies the legitimacy of the hierarchy of credibility' (Roberts, 1990:15).

In a similar way users of mental health services have noted that they may be invited to participate in the process of service design and evaluation, yet when they do so in an articulate way, they are often accused of 'being unrepresentative, of being professional users' (discussion at the Mental Health Task Force Conference, Gateshead, 1993).

By adopting an unconventional methodology, and in revealing the extent of my personal involvement in the issues, I run the risk of being accused of 'bias'. It is conceivable that such accusations may not solely reflect concerns over method, but may arise as a consequence of challenging professional practice in this area.

Action Research

Convinced that good research develops from the integration of theory and professional practice I sought to combine these elements. However, I was daunted by the lack of such practice. This difficulty is raised by Croft and Beresford who note that the spokes people of social work lack representatives of actual service users and *practising* social workers.

People with recent experience as practitioners or users of social work are as rare as a hen's teeth. How many of social work's professors and senior academics have practice this side of the Children Act? (Croft and Beresford, 1995:7).

With this concern foremost in my mind the methodology borrowed from the inspiration of action research. I had been conscious as a practising social worker of the failure to successfully link practice and research. Managers and academics may *once* have practised social work but they can soon become divorced from the field. Patriarchal power relations appear to operate where the powerful research and create policy but have little to do with practice. Social work as a profession is characterised by the presence of large numbers of women at the "coal face" and by similar percentages of men in the higher strata. The theory of action research exemplifies a methodology that tackles issues of power in the research process.

Its roots can be traced back to the forties. Lewin, in Sandford, described a cyclic process of "analysis, fact finding, conceptualisation, planning, execution, more fact finding or evaluation; and then a repetition of this whole circle of activities". (Sandford, 1970:4).

Sandford noted that Lewin felt that insight into social processes was derived from instigating change and then evaluating the impact that this had made (Sandford, 1970:4). Cunningham observed that the cyclical process of action research led to problems being redefined and made the process flexible (Cunningham, 1993).

Action research carries a commitment to democratisation in the research process and also suggests "that organisation members are better able than anyone else to define their problems and propose solutions for them" (Cunningham, 1993:216).

The researcher can act as a consultant, helping groups acquire the skills to investigate problems and then make the findings available to policy making bodies to argue for change. This approach can be used to help disadvantaged groups. Such groups often lack the resources or skills to advocate their needs in the political forum. It also rests comfortably with the social work profession's commitment to the empowerment of actual users of services.

Earlier work within this school was associated with the community development projects of the seventies. Town noted that workers helped communities by stimulating debate and innovation, applying a model of action research (Kingsley, 1985). Initially I felt that I could only make reference to action research, and that as a model there were problems with its literal application to mental health. Many users and their families exist in isolation, and though some are motivated to join organisations, there are many who reject this form of self advocacy. Some carers are too caught up in the business of survival to have the opportunity to participate. The concept of community, especially when applied to mental health care, remains problematic and the notion of the community involving severely mentally ill people an ideal. I believe, however, that it is possible to employ the spirit of action research. The subject of the research can reflect the agenda of those who use the services and the findings can be shared with them.

Instead of appropriating the products of research and disseminating them only amongst professional audiences, they can be seen as the moral property of the study group and shared as an impetus for change.

Action research theorists have not tried to suggest that as researchers we should have to adhere only to the research goals of the clients or community. Rapoport felt that one could combine a search for scientific knowledge with the expressed needs of the community, and work in a spirit of 'joint collaboration within a mutually acceptable ethical framework' (Rapoport, 1970:49).

Close contact with the subjects of the research avoids the danger of exploitation and what Rapoport has called 'parasitical' research that meets the needs of the researchers alone (Rapoport, 1970:506). He also noted that collaboratively produced research is far less likely to be rejected by the subjects who will have been consulted in the processes leading up to the final writing. I had the opportunity to observe a process of what Rapoport called the 'rejection phenomenon' (Rapoport, 1970:509) when some research concerning the work of a social work team was conducted. Although subjects had expressed some dissatisfaction during the interviews, they felt that the final report, produced without recourse to them, was inaccurate, and no one would endorse its contents. Some prior negotiation with respondents about the expression of sensitive areas might have avoided this.

From the beginning of the study I made a commitment that the research and its findings belonged to those involved in the study. I wished to resist a situation where my career might flourish through the study and I might become increasingly distant from those whose lives it represented. This made it vital to use the research in an 'action' sense and to seek change in areas that lent themselves to the application of policy. This commitment was strengthened by the negotiation of my new identity as a carer and the ways in which 'their needs' were now also my own.

I needed to reconsider the issue of community involvement. Some carers were organised and groups such as the Northern Schizophrenia Fellowship (later Mental Health Matters) had represented carers' needs in the region for some years, but many families were isolated. Some did not want contact with others through support groups and others were overburdened. It felt unreasonable to expect people already stretched to the limit by the responsibilities of caring to shoulder an additional burden outlined in the action research model. Given the situation, I felt I carried the responsibility for sharing arising themes and policy implications with those who were not in a position to participate. This could be done on a one-to-one basis and through my contacts with existing groups. To

date the research has spanned from 1991-1997 and during this time user/carer groups have constantly evolved and disappeared. It is however anticipated that Mental Health Matters will launch a forum for carers of mentally ill people and this research will be disseminated through it.

Reflexivity

The research has also drawn on literature concerning the methods of 'ethnography'. Writers of ethnographic accounts have drawn attention to the role of the researcher in the study and have advocated the need to make the researcher's role visible. Hammersley and Atkinson feel that both positivism and naturalism fail as approaches to research. The positivistic approach demands rigour and a standardisation of method that can eliminate the personal bias of the researcher (Hammersley and Atkinson, 1990). Hence every attempt is made to render the process value neutral. Though this approach may be applied in a less complicated manner in the natural sciences its application in the study of human interaction is unrealistic. Meaning in human society is not static but emerges through a process of negotiation of which the interviewer is part.

Hammersley and Atkinson also suggest that the approach of naturalism fails by attempting to make the researcher an empty cultural vessel who can 'surrender' themselves to the culture (Hammersley and Atkinson, 1990:14). This latter approach reflects the quest for the epistemological grail of the 'real nature' of social life. Woolgar refers to Clifford who rejects the notion that there can be a *tangible social reality*, the sole preserve of its natives, and that the researcher should submit themselves totally to it, and thus convey it in all its purity. Instead 'Clifford advocates the dispersal of ethnographic authority in the sense that both researchers and natives be recognised as active creators of cultural representations' (Woolgar, 1991:25).

Hammersley and Atkinson have suggested that one way to resolve the problem of reflexivity is by acknowledging the researcher's role in the creation of the data. This stance was entirely appropriate for the current study.

The first and most important step towards a resolution of the problems raised by positivism and naturalism is to recognise the reflexive character of social research: that is, to recognise that we are part of the social world we study (Gouldner, 1970; Borhek and Curtis, 1975; and Hammersley, 1982). This is not a matter of methodological commitment, it is an existential fact. There is no way in which we can escape the social world in order to study it; nor, fortunately, is that necessary. We can not avoid relying on "common sense" knowledge nor, often, can we avoid having an effect on the social phenomena we study (Hammersley and Atkinson, 1990:14-15).

Given that the processes that we use in research are the same that we utilise throughout social life, we are able to use ourselves as a 'research instrument par excellence' (Hammersley and Atkinson, 1990;18). We are immediately provided with a point of access into the world of meaning and have the means to attempt to share the experience of others. Given the focal role of the researcher in the creation of the emerging data it becomes vital to make the researcher's biography visible. Roseneil noted that being required to reveal sensitive but influential material about one's self was a demanding and uncomfortable process. It did not always ride easily with one's attempts to project a competent academic persona (Roseneil, 1993). I had acknowledged the need to place the researcher in context as a means of demonstrating how the research had developed and data evolved, but I had not anticipated how revealingly painful the process might become. Roseneil (1993) found her sexuality outed through her attempts to expose the construction of data. As my carer status emerged I could have chosen to abandon the research, or cleanse the data of my footprints. The latter position would have been fundamentally dishonest when surrounded by people whose pain was public property. Accepting the task of using my role as a carer in the research also had great

benefits - it allowed me to observe the emergence of a career in caring as it evolved over time. Concepts and experiences that I had only read about came to life through me, and like a photographer my ethnographic 'camera' was ready to capture events as they unfolded. Like Roseneil I wondered if the exercise was not just 'a self-indulgent excursion' (Roseneil, 1993:182) but the power of the experiences convinced me of the justification for working in this vein.

This exercise would not have been possible had the academic climate not developed to make the portrayal of the personal, of feelings about the impact of the data, highly desirable. May argues that 'an understanding of the feelings evoked during fieldwork (and I include the academic field) should be seen as a source of strength, not weakness' (May, 1993:76). Kelly explains how researching domestic violence put her in touch with feelings of vulnerability as a woman (Kelly, 1988). In this work however, the exploration of my own caring experiences became a central feature, as I could not have observed or collected this data through snap shot interviews, nor would I have known what or how to ask. Current research practice conveniently endorsed my personal exploration. It added depth to the questions I later asked other subjects.

In examining the research process itself I became increasingly aware of achieving ethnographic authority. Hobbs notes that authenticity is enhanced if the researcher appears a little 'singed' by the experiences of fieldwork (1993:49). In his case academic acceptance of his account of trade and working class culture in London was supported by his East End accent. He noted that although an academic novice (i.e. unpublished) he had an aura of authenticity and could make generalisations without being subject to theoretical challenge (Hobbs, 1993:49). He noted that a 'male audience was less likely to question the feasibility of a woman speaker presenting a paper on rape or domestic violence' (1993:49). Given my position as a mental health professional, researcher and as a carer my credentials had become formidable. The position I occupied was better described in terms of power than authority. Although it has been suggested that we can view ethnographic authority as

shared between natives and researchers, who both forge social reality (Woolgar, 1991), the current political climate of the citizen's charter and social work's commitment to the empowerment of users and carers renders a particular kind of power on recipients of services. Given this background it would be difficult for non-carer academics to challenge the work. There was a need to avoid the misuse of this newly acquired academic authority and to back statements with considered arguments and supporting data.

The ethnographical climate permitted the project to emerge and remain within the boundaries of respectable research, rather than as the 'confessions of a carer'. The research's literary style was also given careful attention. The product was groomed and scrutinised behind the scenes, and though we never expressed it in such terms, the task was to decide 'what I could get away with.' How could the material be presented in a lively, rich, and challenging way yet remain within the safe boundaries of constituting a piece of respectable academic work? One's style is measured up against other material of that genre and a coefficient of safe deviance calculated. Atkinson has considered how ethnographic research is written to convey the essential constituents of good work in that category (1991). He observes that written matter is not a neutral form, any more than social life is. Social reality cannot be portrayed literally in the sociological text. It is reconstructed through the medium of academic representation, the latter process being as much one of social construction as any seminal social act. This is illustrated by his analysis of Whyte's ethnographic account 'Street Corner Society'.

The monograph itself is, in the best sense, an artful product. The narratives and descriptions, the examples, the characters and descriptions, the examples, the characters and the interpretative commentary are woven together in a highly contrived product. The world we enter into, as readers, is not a direct experience of 'Street Corner Society'; we are engaged in the interpretation of the society-as-reconstructed, and that reconstruction is coded or inscribed in Whyte's text (Atkinson, 1991:2).

Academic work employs tools of literary 'persuasion' to establish the 'plausibility of its account' (Atkinson, 1991:2) and traditional scientific research would not have sunk to the subjective or personal as this would have detracted from its credibility. Atkinson notes that ethnography appears tantalising similar to non-academic literature but this makes its conventions all the more vital, albeit subtle. Conventional scientific research employs writing a device he calls 'writing degree zero' by the textual maintenance of a distinction between subject and object although the author's presence is implied, he or she is not allowed to impinge on the facility of the natural world (Atkinson, 1991:46). Like the operation of the medical model in mental health, the literary conventions of natural science are virtually imperceptible, but this does not mean they are absent. Atkinson (1991) suggests that 'real science' is no less a product of social construction and an exercise in 'persuasion' than any other literary form.

With its heavy emphasis on the personal, and the realm of emotion, this thesis might extend itself past the safe boundaries of ethnographic convention. Wisdom has it that one should observe the signs, and stretch the rules gently, but not too far. If some conventions have been broken it has been through choice, and the need to take full advantage of the opportunity. This should not render the project any less vigorous or worthy of examination.

Throughout my training in research I secretly struggled with the concept of reflexivity. At an early point I was able to recognise its importance and felt that it was vital to acquire the ability to define it, and obscure my uncertainty.

Reflexivity is all about certainty. It is about the ability to challenge the way the world is seen, and to look again. The process of questioning the form and meaning of social life is fruitfully directed at other forms of data, which were traditionally absent from the analysis. Thus the research process researches itself, and hopefully enhances understanding of the phenomena. It is a wholly uncomfortable process as I keep searching for the *facts*, the truth, something solid that I can present in my thesis. As each layer of understanding is

unpeeled and scrutinised, there comes a feeling of relief. 'This depth of analysis must be enough, now we have the facts, aren't I clever, this will satisfy them that I have searched far enough under the surface for the *truth*.' The skill must lie in developing analysis that is fluid and never becomes calcified in the presentation of fashionable received wisdom. It is also about knowing when and where to stop, in order that findings can demonstrate relevance and make some impact on people's lives.

Theory Generation

Hammersley and Atkinson have drawn attention to the unsatisfactory nature of some ethnographic research. While the positivists sought to establish laws illustrating regular relationships between phenomena, naturalism rejected such an approach suggesting that social life was far too complex to permit the demonstration of casual relationships (1990). Many are not only subject to a multitude of factors, but they are also active in responding to such influences. Externally similar phenomena may hold very different significance for people from differing cultures. The task of ethnography had been viewed as the accurate portrayal of a culture but Hammersley and Atkinson reject this approach and remind readers that the task of academic social research is to produce theory. The researcher should not fall into the trap of relativism where they feel unable to comment on the features of a particular social form but merely seek to reproduce it.

One of the most significant assumptions built into naturalism is that all perspectives and cultures are rational. Understanding a culture becomes the first requirement and any attempt to explain it in terms of material interests or ideological distortion is regarded as incompatible with such understanding (Hammersley and Atkinson, 1990:13).

It is tempting to evade the question 'What am I really trying to do?'. Perhaps the exercise is predominantly journalistic with some academic pretension (given the assertion that sociological work should generate theory as well as

provide description). Some ethnographers might have escaped the need to address theory by focusing on the presentation of social reality, by telling the story as 'it really is'. No doubt I might manage to carry out such an approach by claiming ethnographic authority and tyrannising critics with my consumer insight. Hammersley feels that this position of claiming to represent the *truth* represents a *naïve realism*.

Description can never be pure, suggests Hammersley, one may instead present an account with one's theoretical position made opaque, and hence accessible to academic scrutiny. This is the position that I propose to adopt.

Given my intention to work with a small number of respondents the study might be subject to accusations that it will be limited in its generalisability. It may succeed in portraying the concerns of a group of people living in the North East but can it help us understand the needs of a wider population of users and their families? Hammersley points out that theory is an attempt to demonstrate causal relationships between phenomena. It possesses wider significance than an explanation of the processes involved in the causation of a single event. He points to a

need to draw a distinction between explaining (in the sense of trying to show why a particular event or feature occurred) on the one hand and what I shall call 'theorising' on the other. In theorising the aim is not to explain a particular event but to develop and test a theory, an interrelated set of propositions making claims of a conditionally universal kind about general classes of events. Here propositions relating to particular factors are included or excluded according to whether or not they seem likely to form part of a coherent theory. Our primary interest is not in the events themselves. Instead their only significance is the opportunities they provide for developing and testing in theory (Hammersley, 1992:38).

The quest for predictive laws in social science has largely been abandoned. The range of variables is infinite, yet many sociologists would attempt to establish 'quasi laws' or 'intelligent principles' (Hammersley, 1992:41) that might offer an understanding of events beyond the level of the individual case. In seeking policy change and the provision of funding for care we need to demonstrate the likelihood that a category of families will experience particular needs. If this can not be established the work will only represent the story of a small group of unfortunate people.

Claims to generalisability made by survey or experimental research are founded on sampling procedures and probability theory. However, Hammersley (1992) notes that research rarely has the luxury of examining *all* the subjects in a particular statistical universe, and practicality demands that stratified samples must be used. This procedure is dependent on the identification of all the salient variables. Though many such as race and gender are known, the researcher is logically unable to know of the existence of the complete range of factors that will have a bearing on their subject. Recognising the limitations of sampling technique, one may assert that non random samples can yield results generalisable to wider groups, provided careful attention is paid to known sources of heterogeneity (Hammersley, 1992).

Glaser and Strauss (1968) attacked the testing of hypotheses generated in isolation from the field. They have argued that if theory is built inductively through empirical examination, it cannot be wrong. Popper would have rejected this approach. He asserted that single experiences were logically incapable of proving casual statements of a universal nature. One would have to examine an infinite number of experiences to verify the statement. To fail to do so would always carry the threat that further investigation would reveal that the proposition was false (Popper, 1972). He also viewed the subtle modification of hypotheses in the face of contradictory evidence as unsatisfactory.

In daily life our existence is based on experimentation. We make (probabilistic) judgements about the world around us. At times these may fail us, but they are associated with a satisfactory degree of success. Though theoretically our working hypotheses are open to subsequent falsification they are justified pragmatically. It appears that the processes of hypothesis-generation, and empirical exploration can not be isolated. Ideas are conditioned by cultural experience and though hypotheses are subject only to empirical falsification, (Popper, 1972) they continue to provide useful tools in our attempt to understand (and predict) the world. Although induction and deduction may be philosophically distinct they are empirically intertwined. A comparison exists between this problem and the debate on the epistemological distinctness of quantitative and qualitative methodology. Bryman concludes that the two traditions may be philosophically distinct but it can be deduced from much research design that they are methodologically neutral (Bryman, 1984). While it can be useful to draw conceptual barriers around the field of study there are occasions where the debates can not be further resolved, and one needs to 'get on with the job'.

The debate concerning theory is less clear on inspection. It appears that theory is a statement about casual relationships between phenomena. At what point does an explanation (Hammersley, 1992) become a theory? What size must the group of phenomena be before explanation merges into theory? To demonstrate universality theory must logically lie outside of empirical reality and its validity would be dependent on values set at infinity. Such an approach is ludicrous. Beyond examining the explanatory factors demonstrated in an individual case we are often able to form useful, working theoretical models based on data from moderate sample sizes. Such theory can not be definitive but it provides a bench mark that enriches our understanding as it is continually redefined. I would therefore assert that small as this study is, it is capable of providing pertinent theoretical insight. Such theory will not be definite but lies open to subsequent modification.

The Interviews

Although this study is based on data gathered from thirty semi-structured interviews, as previously indicated information was gathered through a range of additional sources (this included attendance at groups, professional and voluntary work). Information was interpreted against a background sensitivity gained through intense contact with the phenomena (see Glaser and Strauss, 1968 for a discussion of theoretical sensitivity). My personal experience as a carer also led me to be suspicious of the ability of 'snap shot' interviews to reflect what could be described as an ongoing struggle. In particular a single interview can fail to reveal the ups and downs, the hopes and disappointments and for many the reality of chronic suffering. As one woman said some weeks after the formal interview, in tears over the phone, "You saw me on a good day". This knowledge has made it important to retain contact with a number of carers over a period of time which has given a fuller picture of their experiences.

I have however rejected the suggestion that I could recruit people in crisis, for example at a compulsory admission to hospital and then follow them intensely. Although I might be able to offer extra support as an incentive (and a moral justification) I could not come to terms ethically with such an invasion of privacy. At such times families are exceptionally vulnerable and the validity of their consent would be questionable. I have therefore chosen to use the material about my own experiences to illustrate the nature of crises and the experiences of caring over time. The study coincided with the development of my partner's illness and has traced it through relapse and remission. It recognises the development of one's identity as a carer, and how the caring role alters with the unpredictable, and at times dramatic changes in the user. It has provided flesh to the study's incipient structure and opened new areas to explore with carers.

The interviews were mainly taped but this proved problematic from the beginning. It was not difficult to persuade subjects of the benefits of taping (for the study!) but many people were clearly uncomfortable. Taping seemed to be more threatening than recording manually. It seems to preserve one's experiences in their entirety, and although subjects know they can be quoted verbatim from notes, the preservation of voices, tears, feelings seems unnecessarily intrusive. Bearing in mind the ethical basis of the study I decided that the families' needs should be paramount and that if people appeared at all uncomfortable about the tape I would use notes alone. Where I have made tapes I have agreed that they will be for my use alone and be destroyed after submission of the thesis. Stevens (1972:21) noted that interviewing mentally ill people with a tape recorder could exacerbate paranoia.

It was rarely easy to see the 'carers' alone. The 'patients' were often curious, suspicious, or wished to contribute in a positive way. There were occasions when the sufferer came home unexpectedly (my presence would have been very unwelcome in some cases) or was in bed and the interviews had to be conducted in the best way possible. In any case people are frightened by mental health workers (one woman had been sectioned and taken away by the police), or suffer paranoia and often believe that hostile agencies are bugging their houses and minds. In such circumstances the use of video or tape recording is ethically untenable.

At times the interviews were carried out in very noisy conditions. One woman was cooking as she had to attend an unexpected hospital appointment, and the interview had to be carried out in the time available. The subjects were often busy (and so was I). At one stage interviews had to be cancelled as I felt it unwise to stay away from home because of my own caring responsibilities. I am learning continually of the demands that the caring process places on the carer and their working life (the conditions faced by women academics, and by women in general as they attempt to compete in employment, are widely recognised). Carers of people with severe mental health problems must

balance the demands of caring and maintaining an income within a societal frame work that may not recognise that they are doing anything at all.

The interviews were rarely what I expected. Despite my wide ranging experience as a social worker I was continually educated by the people with whom I came into contact. Attending an ESRC course in qualitative analysis in 1992, a woman academic described her feelings during her early fieldwork. Talking to women on a deprived estate about their experiences she had found the prevalence of abusive relationships and hardship difficult to cope with. My experience as a social worker and as a Samaritan provided training in the skills of interviewing people about what may be termed 'sensitive subjects'. It provided experience in surviving exposure to emotional trauma. Basic counselling skills, such as listening and empathising with the subject, remain fundamental if one is to carry out interviews in a sensitive way. This means that carrying out the interviews can be a very demanding process.

My appreciation of what might be likely issues for people was continually redefined by contact with the families, and as my own understanding of the process of caring intensified. I lived experiences that sufferers and their families had told me about, but somehow I had failed to grasp. It seemed as though my professional paradigm had acted as a filter and sifted through people's responses. It had only allowed me to acknowledge the relevance of particular aspects of people's needs - those that had received professional sanction. It also served to dilute people's distress.

It was difficult to know how to deal with my own experiences during interviews. Did I attempt artificially to conceal them? I concluded that I would not be able to explain to people how I had become aware of certain features of the experience unless I was honest. After all what would be the reason for concealing my status as a 'carer'? Working in a field where stigma is rife and where professionals make statements about openness, I was adamant that I would not condone double standards. I recognised that this might make my role difficult in relation to other professionals. The system did not seem to

recognise that people frequently occupy several places in the scheme of things. My perception is that the data gathered is of a richer quality. Carers and other users of the services feel aggrieved at times by the flow of professionals collecting information. I often encountered carers who said that my status as a carer made me more receptive to their experiences than someone who was merely a professional. As one carer said, 'After all you are one of us now'.

At times I felt overwhelmed by the things that people shared with me. Subjects came to the session with their own agendas and it would have been inappropriate to refuse to provide support during the session if they indicated that they needed it. I have heard it argued that one may deal with this dilemma by confining one's role to research, and that one cannot be expected to provide emotional support (people's expectations of support might have been intensified by their knowledge of my professional status). I suspect however, that the exploration of difficult experiences would stir up such needs regardless of the role of the interviewer. Some carers stated explicitly that they expected the interview to offer them support and said that they had received it at the end of the interview. During some sessions the tape recorder was stopped so that people could cry and to allow me to attend to them fully.

I constantly sought ethical guidelines about what I was doing. Honman notes that ethical guidelines used in research derive from codes of medical ethics. Hence, the 'interest of science and society should never take precedence over considerations related to the well-being of the subject' (Honman, 1991). However, he recognises that informing the subjects of the purposes of the research may be reduced to offering 'a highly generalised and anodyne account and avoids any probabilities that might disincline intended subjects from participating' (Honman, 1991:75). The application of research ethics is complex and defies reduction to rule following. The problem extended to the inclusion of material regarding my own family, and at least one professional tried to counsel me against its use. My partner and I have, as much as anyone

can, considered the disadvantages and given our informed consent. Somewhere is the notion that the exercise might help others in the future.

Things might have been much neater if, in Brandon's terms (in relation to the role of the approved social worker), I had been able 'to play God' (Brandon, 1991) by being able to comfort from a position of professional superiority and distance! Instead I became increasingly entangled as my own life continued to unfold like a script for 'Casualty'. I could only adopt Egan's advice, that the helper should do no harm (Egan, 1990) and that personal and professional ethics should be synonymous. Any support given should be given in the spirit of empowerment and within a framework of confidentiality.

The Sample

The selection of a sample represents a compromise between theoretical desirability and pragmatic constraints. This topic was chosen as I felt fairly confident that I would be able to find subjects (an alternative thesis topic was rejected on the grounds that access might be difficult). I was conscious that an outsider might have experienced problems in obtaining access especially from the statutory agencies. The difficulties experienced by Ruane in her work on adoption illustrates this problem, (Ruane, 1990). Health and Social Services can adopt a position of shielding their patients/users. This may represent a well-intentioned desire to protect vulnerable people from emotional trauma, but may also represent an attempt to avoid having their services exposed to critical evaluation. There may also be a resistance to interference by people they perceive as 'unqualified'. Given optimal resources, I might have chosen to meet carers from a wider geographical area and ideally to have examined caring experiences outside of the UK. Evidence suggests that, as the course of schizophrenia is not as severe in less developed countries eg. India, and, as their access to medical resources is minimal, social support appears to play a crucial role in determining recovery patterns (see Warner, 1994). My own caring role and work responsibilities limited me to conducting a local study which can only provide an initial impression of carers' situations, and further

work will be essential to verify and build on the findings. Working to the regulations of part-time registration the degree committee suggested interviewing around 30 people. It was stressed, however, that the 30 should be selected to illustrate the fullest spectrum of experiences, attitudes, and salient variables. The selection of an 'adequate' sample being fundamental in determining the quality of the data.

Glaser and Strauss have advocated a model of 'theoretical' sampling where the researcher does not choose their sample at the outset, but will seek a range of subjects, or experiences to study according to the demands of theoretical innovation. As themes emerge the grounded theorist seeks situations that will help them explore these new aspects. They rejected the conventional approach where the study group was agreed at the outset, and any diversification was regarded as indicative of dangerous personal bias.

Data collected according to a pre-planned routine is more likely to force the analyst into irrelevant directions and harmful pitfalls. He may discover unanticipated contingencies in his respondents in the field, but is unable to adjust the collection procedures or even redesign his whole project. In accordance with conventional practice, the researcher is admonished to stick to his prescribed research design, no matter how poor the data (Glaser and Strauss, 1968:48-49).

The first group of respondents in the current study was drawn from the caseloads of social workers in the mental health team in which I worked. They were not selected at random from a register of patients' names, but represent an exercise in what has been termed 'judgement sampling'. Honigmann notes that the ethnographer uses judgement sampling most effectively when 'it is informed by expert knowledge' (Honigmann, 1982:80). In this case judgement was informed by an Approved Social Worker's understanding of the range and impact of mental disorder on patients and their families. This perspective was later broadened by complementary 'expert' knowledge as a carer. This research does therefore reflect sources of heterogeneity as perceived through

the eyes of a mental health social worker with latter experience as a carer. Had the sample been chosen by a psychiatrist, a psychiatric nurse or a user of mental health services the results may have been quite different.

The first subjects were approached in what is the traditional way within medical practice. A written approach and subsequent presentation was made to the local research ethics committee. They found the concept of working with a small group (ie under that required to achieve statistical significance) that was not drawn from random difficult to equate with. The process of approval was eased by the support of a sympathetic psychiatrist who acted as an ally.

Unless one has the capacity to interview everyone 'sampling' is inevitable (Burgess, 1989) but to consider everyone in a numerical universe is a logically elusive exercise. Decisions on where to draw conceptual boundaries are necessarily subjective. Rigour is a matter of degree not an absolute, and so judgement sampling should not be maligned in contrast to stratified sampling, as being 'opportunistic' or 'convenience' sampling (Honigsmann, 1982:80). Any attempt however well conceived, to balance the study group will be inadequate, because it is logically impossible to anticipate all sources of relevant diversity. Hammersley observes that most quantitative studies apply stratified sampling rather than pure random sampling. 'Stratified random sampling, for example, involves reliance on background knowledge about the most significant forms of heterogeneity to be found within the relevant population' (Hammersley, 1992:88). Such sources of heterogeneity are traditionally viewed as gender, ethnicity, social class and age. In this study one might add the characteristics of the sufferer, ie their diagnosis, the severity of their symptoms and their relationship to the carer. Although these features provided a starting point, other unanticipated characteristics soon emerged as significant and I would not have been able to build these into a stratified sample at the outset.

The sample of three people caring for someone with dementia was obtained through the agreement on the local psychogeriatrician (the sympathetic member of the ethics committee!) and unit social worker. Under ethics

committee protocols I would have needed to obtain prior consent from the older people before speaking to their carer. Given their lack of medical competence I sought the consultant's consent as an alternative. A fourth subject caring for someone with dementia was contacted through the university. The person she had cared for had died and I approached her directly.

It would probably have been possible to have spoken with other carers of people with dementia, but given my limited resources I was anxious to focus on adults with mental health problems. There is rather more written about carers of older people and I believed that the data gathered from the four dementia carers could provide an adequate theoretical contrast.

Having seen a number of carers of people in the locality where I worked, it felt appropriate to diversify. These users and their carers were all within the psychiatric system. The patients had seen a psychiatrist and had problems severe enough to merit the involvement of a social worker. More significantly ethics committee protocols required each sufferer to consent to my approaching their carer. This immediately restricted the group to sufferers who were amenable to professional involvement with their families. My experience as an Approved Social Worker suggested that some sufferers 'lacked insight' and might be hostile towards family. This meant it was essential to seek additional subjects without prior recourse to sufferers.

Contact was made with a self help group whose membership included carers, users and the odd professional ally. I attended meetings and then saw two of the carers privately. The people they supported would probably have been unwilling or unable to give informed consent to their carer's involvement in the study.

Having interviewed people contacted through my own mental health social work team and through a local self-help group, it was apparent that the range of experiences was partially dependent on the personal clinical style of the psychiatrists in that area, and also on the practice culture of my own team. It

was necessary to go further afield to have the opportunity to observe potentially different experiences. By attending a carers' group held under the auspices of Mental Health Matters contact was made with four carers in the north of the region. There was no requirement to meet with or consult the people they supported. A further selection of carers was interviewed following an approach by letter made through the Mental Health Matters Carers' Counsellor. These people lived across the north of the region, in various urban boroughs and in the surrounding rural areas. People who were in contact with the carers' counsellor had usually been referred for support by statutory workers, some had made self referrals, others were actual members of MHM committees and therefore felt that it was important to support the study. Contact with the MHM group suggested that they were distinct from contacts made through the caseloads of colleagues. Their problems were often severe and statutory (Health and Social Services) help had frequently been perceived as unsatisfactory or non existent.

Most had experienced significant difficulties in their caring situation. Their dependent relatives could be distressed, disturbed, unpredictable and would have been unlikely to agree to my interviewing their carer.

The study has attempted to draw on a variety of carer experiences. It is important to include carers outside 'the system' as they might be the most in need of help. I cannot suggest that the study is complete and that the research has 'saturated' all pertinent variables (Glaser and Strauss, 1968:61). Although increasing contact with carers has reinforced the recognition of common experiences, I continue to be surprised by the stories carers relate and of the intensity of suffering that some families are continuing to face.

The individual carer was chosen to be the unit of study. It might have been relatively simple to use self-help groups or to have created carers' forums specifically to elicit carers' views. I suspect that this approach would have been unsatisfactory. Groups are not for everyone and some people prefer the privacy of one-to-one contact. From my own experience I am aware that when I

most needed help, I would not have been able to leave my dependent relative safely. Carers are busy people, and those who are ill cannot be easily supervised by a 'sitting service', such as those used for dementia sufferers. Additionally some people do not seek group involvement because of the dynamics of group membership, or because their relative's situation is stable and they have other things to do with their lives. Additionally confidentiality may be an issue in rural areas and deter rural carers from membership.

The pertinence of time as a sampling filter (see Brookover and Back, 1982), emerged as a crucial issue. Mention has already been made of the attempt to incorporate a longitudinal approach through the use of personal material. 'Snap shot' interviews may not do justice to the presence of a considerable variation in distress and may lead to complacency in professionals. I have used ongoing contact and personal material to illustrate these fluctuations. It might have been desirable to provide longitudinal material on a larger number of respondents but this approach could be attempted at a future date.

There are inherent problems in asking people to share difficult, painful material especially as it is happening. Like war photography, one is torn between the desire to describe and hence promote understanding, and the dangers of sensationalism which denies human dignity. In providing adequate description it is difficult to protect confidentiality fully but, except in examining my own family's experience, I have tried to balance the need to provide a full account with the protection of confidentiality. Where description would expose individuals I have chosen not to use the material.

Data Collection and Analysis

The interviews were initially analysed in groups of about five subjects. The data were evaluated and results used to inform the next phase of the research. As the study progressed the final group of a dozen interviews was conducted as a single group. At this point I had been able to contact people through the carer's counsellor and wished to respond to the contacts as quickly as

possible. My own caring responsibilities made analysis at that time impracticable. The interviews were recorded and analysis conducted almost a year later - initially in May 1995.

Each tape or collection of notes was translated into verbal notes which were audio typed into a transcript. These transcripts were the basis for the coding of themes and subsequent written work.

It would have been satisfying to be able to recount the process of analysis as an ideal. Unfortunately the period of study was constantly interspersed by computer difficulties. During the five years of registration I repeatedly sought access to a stable source of secretarial support and word processing but was unable to achieve this. The situation was in part due to my changing employment and to the instability caused by the retraction of the psychiatric hospital. It also reflects the low priority given to research carried out by social work practitioners and the difficulty people living in rural areas with domestic responsibilities face in using centralised resources. Although I had ESRC funding I was told that this could not be used to buy hardware as I had adequate access to the University facilities. No one arrangement proved enduring and I coped - by the skin of my teeth.

The lack of a single source of word processing made using computerised software for the analysis of qualitative data virtually impossible. Despite constant alluring promises of access to machine and software I felt it necessary to decide to progress - manually. The study was to be concluded with felt tip and wallpaper and not with current state-of-the-art technology.

There can be little doubt that in conducting larger scale studies the use of computer software can be efficient and can remove a great deal of drudgery and facilitate links between concepts (see Dey, 1993), but this process can still be conducted with highlighter pen and scissors!

representativeness

The use of qualitative methods entails complex issues around the question of representativeness. In this section I will try to address some of these concerns. but as with many problems of method there may remain substantial issues that are only partially addressed. While it is quite fashionable in academic circles to include personal material, even a methodological requirement in some circles, I have taken this process further and included myself as a respondent, as well as the editor of the text. It is increasingly acknowledged that ethnographic accounts do not replicate reality, but in common with quantitative research actively select and interpret the social action in question. Indeed, Hammersley notes that the claims of ethnographers to replicate reality are fundamentally flawed.

One of the most common rationales for the adoption of the ethnographic approach is that by entering into close and relatively long term contact with people in their everyday lives we can come to understand their beliefs and behaviour more accurately, in a way that would not be possible by means of any other approach (Hammersley, 1992:43-44)

He suggests that ethnography has made claims to enhanced 'realism' ignoring the role played by the researcher in interpreting the events, in selecting from the greater body of experience, and in the way that the information is presented. When I have included the actual words used by the respondents they are never offered in a *pure* form, but are understood in the context through which I have presented them. I have recognised and responded to my own role in constructing the data and have attempted to retain this awareness throughout. However, in arranging the material for inclusion in the account decisions have had to be made as to the ways in which information has been offered to the reader for interpretation. This can never be a neutral process.

Dey (1993) asks that research accounts be made accessible, that they should engage the reader and involve them in the plot. In this respect the account has similarities with a work of literature, or in this case an autobiography. Indeed there is apparently a new genre in the autobiographical of misery. (Judging the response I have received this work belongs to it). In the Independent, Appleyard questions these public revelations by murder victims' relatives and asks whether they serve any purpose than the removal of the victim's dignity (Appleyard, 1996:2-3). There is a danger of hiding emotional catharsis under the guise of academic theory. Dey reminds us that though research should be interesting to read, its purpose is not to entertain but to *analyse*. In order to satisfy questions about the relevance of the current study I need to demonstrate, not that the account is an exciting story that will shame mental health professionals, but that the theoretical account has been crafted with due regard to the representativeness of the material on which it is based, that deductions have been made with scepticism about the weight of the evidence that underlies them. (Otherwise a good journalist would do a better job of advocating for carers).

Where the researcher's autobiography is given, it allows us to assess the characteristics of the human tool that collected and shaped the data (see Rosneil, 1993). Given the fact that the use of material by and about the researcher is so prominent in the current study, to what extent is it the analysis of a single case? Informative as the data are, what relevance can the findings have for other carers? There may be questions about the generalisability of the findings.

In order to satisfy these questions it is helpful to scrutinise the methodology and the ways in which the data were analysed. Areas that could prove informative include the amount of material concerning the researcher, its intensity, content, and the degree to which the theoretical account depends on it. A superficial inspection reveals that material about the researcher appears throughout the thesis. It is accompanied by material about the other thirty respondents, but the autobiographical script takes up more physical space. A

typical entry from the researcher's caring diary being about ten lines long compared to direct quotes from the other respondents which rarely exceed one or two sentences. The diary entries are often laden with emotion and the other respondents' comments tend to be less emotional and more descriptive. This could suggest that the experiences on which the autobiographical material was based were inherently more dramatic than those of the other respondents and that they made a far more exciting story than the mundane comments of the majority. Perhaps the respondents did have occasional dramatic experiences but these were the exception to the researcher whose life was constantly interrupted by life threatening events. Given these questions, are the theoretical deductions justified?

Other researchers have used diary material. Plummer draws attention to the fact that although diaries are supposed to be written daily and may help us to understand the longitudinal processes, rather than the freezing of social life through the static snap shot, at the interview they are also single entities from which particular material will be selected and other data ignored (Plummer, 1983:19). When selecting material from the diary I tried to be aware of the need to balance the data I drew. I tried to write about the quiet times as well as the horrific. This meant making a conscious effort to record what I considered to be *normality*, even when I felt I had better things to do. Of course whether during an interview or when writing a diary, one's current experience will colour the content of the past.

There is a body of respectable literature that could excuse me from this exercise. Hammersley notes that feminist researchers have conveyed a number of important criticisms about the phallocentrism of much mainstream research and have queried the conventions of establishing methodological respectability. Feminists have asked that personal experience be given the recognition that it deserves (Hammersley, 1995:46). I have already drawn on such sources, earlier in this chapter. They support the adoption of personal material as valid data, rather than as an untidy complication in the way of collecting objective knowledge. Research shows that caring is frequently a

women's issue and this alerts us to the need to look at women's feelings and subjective understanding of the caring task, as well as those of professionals. This makes the adoption of feminist method appropriate but it should not be an excuse to avoid critically appraising the way that data were gathered and presented.

In his review Hammersley goes on to discuss feminist descriptions of a second reality, one not easily accessed by men who belong to the social mainstream. (1995:47) However, though this material supports my use of personal accounts as data, including my own experiences, it does not permit me to generalise from my experiences to those of all carers, or all women carers. I have a vested interest in trying to convince the reader of the soundness of my arguments, but at the end of the day this is not enough. Dey argues that so many qualitative researchers justify the soundness of their work through claims to personal integrity (1993). The fact that I am supposedly a nice person and a conscientious social worker does not avoid my making errors that may arise from my inability to recognise data that fails to fit with my expectations. Although the reader is ultimately dependent upon my integrity it is appropriate to search for additional evidence.

Dey suggests that researchers should make their analysis open to inspection. That readers should be able to access 'the workings out', to be able to inspect examples of coding and where decisions were made about the inclusion or rejection of conceptual categories. I lacked this material, having coded on successive pieces of paper rather than through the cyberspace of a qualitative data analysis programme. It seemed sensible, therefore, to return to first steps and to attempt to re-categorise material from the respondents, ignoring the data about my own situation. I could not, of course, wipe the understandings from my consciousness. As a carer I had formed categories and quasi-theories about the caring experience and could not destroy these. I did, however, have the benefit of one of my own observations, that the painful experiences of caring are quickly erased and forgotten. Only yesterday a carer explained that 'when things are OK you quickly forget how bad things were'. At present I am

able to take advantage of this phenomenon, being what a colleague has termed a 'carer in remission'. On the basis of this I decided to re-analyse the respondents' material.

This felt like a potentially threatening experience because of the risk of illuminating significant bias in what I had hoped were the latter stages of the write-up. In fact I have concluded that the exercise has been particularly valuable and now has increased my confidence in the study findings. The re-analysis confirmed earlier findings and I could form the overall account without the added material from the diary. Hence I feel that I have been able to demonstrate an increased level of internal validity (see Dey, 1993). On the basis of this second analysis I have chosen not to alter the final account.

What the respondents' material provides is a cryptic account of the caring experience. To the sensitised ear their stories betray the presence of a range of experiences that they rarely articulate fully. They do not explain word for word what happened and how they felt. There are a number of possible reasons for this. It is not usual to describe very deep emotions to a stranger. I had asked questions about factual events and experiences and they had replied within that framework. They often said that it was difficult to remember and the events were related in a non-linear fashion. At times people did become upset but taken word for word their accounts could not equal the amount or usually the intensity of the diary material. The diary caught feelings and events within 1-2 days of their happening and encouraged a full description. The diary represents a carer's experience constructed in a particular form, it is an entirely different way of encoding social reality to the interview.

Some data was the product of families that I had known for some time, or where I had returned to talk further, rather than conducting a single interview. During such return visits one is able to see a shift in the type of response elicited from factual description to deeper feelings. An example of this was with a man caring for his wife. Although I understood that she had been very ill and had

had several difficult periods of hospital treatment, it was after a subsequent visit that I commented on how I felt that I had not *really* understood what had happened in their home. He told me about how his wife had been fuelled by delusions, was in and out of bed 21 times in one night and had gone berserk demolishing their Christmas tree. He had felt threatened himself, but also had to try and look after their children. I believe that when carers tell us about *events* that have happened they need us to be able to read between the lines. Professionals gathering information about facts of interest to them are likely to miss such detail, without which they cannot understand the carer's perspective. I believe that this material differs significantly from that collected during a semi-structured interview with a stranger. It represents a midpoint on a continuum between reality encoded as events (the interviews) and reality as personal experience (the research diary). The detail taken from my own story could actually have been about virtually anyone mentioned in the study. This is often given in full because I had in-depth material written in a style that reflects feelings and experiences. It would, of course, have been helpful to have had such accounts about others but that would have involved a range of ethical and methodological difficulties about the invasion of privacy and observation of distress.

Given that the issue of balance between the autobiographical data and the respondents' material has been addressed, we now need to explore the way in which representativeness has been approached within the individual subjects' cases, and between them. I have suggested that at times the subjects offered clues to the depth of their emotional experience, and I believe that my sensitivity to the data allowed these themes to be made explicit. It could be argued, however, that I simply heard and emphasised things that I was looking for, ignoring material that conflicted with my theory. I did, however, attempt to treat all material with some degree of scepticism and sought to highlight material that was in direct conflict with the emerging theory. Rather than being a problem such data breathes life into the research. It is by understanding the

reasons behind difference that we have the opportunity to search for mechanisms that may permit change.

The same approach was applied to the differences between cases. In particular I sought to highlight the contrasting long term outcomes. While many families continued to have difficulties and seemed to live from one hospital admission to another, some users were actually quite well. In addition some carers had reached an acceptance of their relative's illness despite the lack of improvement. Rather than ignoring such cases, (to play on a sympathy vote?), I sought to understand the range of contributing factors that might be involved. Indeed, it appears that Glaser and Strauss' (1968) suggestion that one looks at contrasts to enhance understanding is particularly pertinent. Rather than emphasising the plight of a group of people, as one might as a journalist, research examines the complexity of social reality and seeks sources of difference as an aid to understanding.

A quantitative study would have made use of categories which could have been quickly translated into numerical codes. Frequency distributions, histograms, and pie charts produce respectable and accessible information concerning the data. It is easy to locate a case in relation to others in the sample through statistical measures such as standard deviation. Although I could have collected some information that permitted this form of interpretation, variables that were salient in the data were not amenable to this form of manipulation. The codes were based around the descriptions, feelings and the experiences of carers, including myself, and did not readily afford a reduction to numbers which would have destroyed their strength. To have allotted numerical values to such codes may have been possible, but would have been superfluous. The complexity of the data was better represented through actual words and phrases. At one stage I did attempt to draw a matrix and included some of the more factual details of the respondents. I abandoned this process when I realised that it added nothing as the tabular detail required verbal explanation. For example, in reporting the number of admissions to hospital that each user had experienced one might have concluded that a low figure indicated a milder

mental health problem, or one that had resolved. In fact this often represented the most disturbed respondents in the study who could not get access to help. I have therefore relied on words alone. Hughes questions why meanings are denigrated as being subjective and are 'only allowed in scientific discourse if placed in quotes and attributed to individuals as their opinion, belief, attitude. What are being referred to as subjectivities are allowable providing they conform to the canon of positivist description' (Hughes 1990: 116)

Plummer advocates the adoption of life histories in sociological research. In particular he cites the 'aridity' of theory. Discussing the model that Strauss used to understand dying he explains how the lengthy exploration of a woman's long, lonely death brings the theory to life (1983:74). It is this approach that I have tried to adopt, because the academic and professional material rarely touches the experiences of carers' lives.

While I am convinced of the value of this account as a vehicle for increasing understanding of the carers experience, it remains just one possible account. For their own purposes professionals may be content with collecting histories that fail to acknowledge the carer other than as family. In accordance with my methodological perspective, to involve the subjects of the research as fully as possible, I have shared the draft thesis with a carer whose experiences are contained in the study. She has told me that the material was very painful. The use of diary accounts made the experiences come alive. She added that 'I did not know whether you were talking about yourself or me. I found it too difficult to read, your words could have been my words.'

Disseminating the Findings

Writing the thesis is not the final stage in this participatory research. I have a moral and professional responsibility to disseminate the findings. Hart and Bond note that action research is not a means for establishing causal relationships, but a vehicle for the empowerment of practitioners. They look forward to practitioners developing their own research skills, and taking

responsibility for the development of a conscious body of practice. Such practice would be continually refined in the light of research findings (Hart and Bond, 1995:21). However, I would argue that action or participatory research can be a means to empower those who actually use health and social services. Carers also seek to improve the ways in which they respond to the needs of those they support. Carers therefore have much in common with practitioners, and in order for professionals to begin to develop better practice they must begin to include users and their families in the conception and operation of services. After submission of the thesis I therefore anticipate disseminating the findings to carers as well as to policy makers and within academic circles.

Chapter Two

Policies, Politics and Mental Health Care in the Community

Although each carer's story is a personal journey, it is constructed and experienced through a common social and historical framework. An examination of the historical context and legislation can enhance understanding of how society reacts to, and copes, with mental illhealth. The very idea of a carer is the product of successive policies and these have been ratified through a number of pieces of legislation. In this section I will look at the background to the situation faced by family carers, by discussing historical attitudes and treatment, moving on towards the implementation of Community Care, to an examination of more recent legislation and the structural changes in the way care is allocated and provided. Having discussed the policy context, I will examine the experiences of carers and the ways in which these are conceptualised, returning to consider the implications for service provision in the final chapter.

Attitudes to Mental Health, Care and the Rise of Psychiatry

A discussion of the needs and experiences of carers is inevitably tied to the social perception of the problems faced by mentally ill people. Community care policy has attempted to introduce common procedures for a range of user need and has emphasised the commonalties between all carers and service users. This shift may feel unconvincing both to service users and carers, and to the non-disabled public when in contrast with the 'legitimately' dependent ie the disabled, older people and those with a learning disability. Mentally ill people, and by implication their carers, are included under sufferance. Stigma remains a reality, and will probably have been internalised by many users and carers prior to their own experience of mental disability.

Mental illness does not only require care but it allegedly requires control, and this often separates it from other forms of care need. Attitudes to mental illness have developed over time, and its definition as illness can be viewed as the ideological ascendancy of particular interest groups. Of course older conceptual models may be only partially displaced, and remain firmly fixed in the social imagination. Such attitudes can not be erased by a few decades or so of community care legislation.

Over the past few years alarm over the 'failure' of community care policies for severely mentally ill people has intensified. It has gained momentum in the months since I first wrote of the tragedies and enquiries in 1995. There have been more multiple deaths (the Tasmanian shootings) caused by people described as 'diagnosed schizophrenics' and more enquiry reports (Blom-Cooper, 1996). The public is probably less motivated than ever to feel compassion towards the 'schizophrenic' but seeks reassurance that the problem is entrusted to safe hands. It is psychiatry that has traditionally succeeded in dominating the care and conceptualisation of the mental illness but this interest was a comparatively recent development, medics were not always concerned with mind illness, but with proper physical ill health.

The respectability of psychiatric knowledge is still unconvincing, perhaps deep down the public does not really believe that mentally ill people are ill at all, and quickly exposes a deeper conviction of their ability to pollute and contaminate the normal population. Of course psychiatrists would maintain that psychiatric science represents the triumph of knowledge over prejudice, Turner notes that the development of psychiatric knowledge is regarded as a linear development in rationality, unmodified by social processes, professional advantage etc. (1987:59).

It is not difficult to find evidence of positivism in psychiatry. Goldberg et al (1994) present such a text intended for doctors in training. It teaches the student the rudiments of examining the patient's mental state, and lists all the 'facts' that the new doctor should have at their finger tips. Supported by

endocrinology, a knowledge of drug metabolism, reference to neurotransmitters and a robust diagnostic framework, the would-be medic is ready to diagnose and treat all known forms of mental disorder, but is, it appears, in this case ill-equipped for critical conceptual analysis. Despite the uncertain philosophical underpinnings of a medical science of mental distress, psychiatry established its professional dominance. Even so 'common-sense' conceptions of mental illness remain poorly disguised beneath the surface.

Prior has subjected the "social organisation of mental illness" to sociological analysis (Prior, 1993:14). Prior's contribution is important, he does not believe that mental distress is a fiction created by social labellers seeking victims for their professional empires, but does ask for an examination of the social processes, professional priorities and economic forces that shape how such distress is constructed and dealt with, personally, socially and politically. 'In Bhaskar's framework, then, we have no need to deny that specific psychiatric diseases and disorders exist, but we can deny that professional psychiatric practice is nothing more than a reflection of those disorders' (Prior 1993:15).

What may be termed the discourse of mental illness can be traced from the latter part of the 18th century. This process laid the foundation for the ways in which mental distress is managed in our society today. The definition of mental disorder as illness implies the need to care for the sick person but as ideological dominance is incomplete and conflicting definitions of the nature of mental disorder co exist with the illness model, the legitimacy of caring remains suspect (priest, probation or police officer might be more appropriate).

Psychiatry becomes the Market Leader

Turner notes that there has probably always been a need for facilities, and practices for dealing with 'disturbed' people. In the fourteenth century there were places where families could put deranged relatives (1987:60) presumably until they had calmed down, but he adds that was no insanity. Any continuity is created by the discourse within psychiatry and that psychiatry is a useful concept for dealing with "troublesome nuisances" (1987:62). Scull (1979)

attempts to trace the development of medical dominance in the area of mental distress, and notes a movement from demonological and theological models to the medical interpretation of insanity as illness of the brain. Medics were not always involved in the treatment of 'mad' people and had little interest in their welfare, but by the 1830s almost all public mad houses were supervised and visited by doctors (1979:168). This represented a triumph of professional muscle and propaganda.

Scull noted a few hiccups in the medical colonisation of mental distress, apparently early medical treatments for mental disorder were rather ineffective! The leechings, bleedings and purgings were no more likely to cure mental illness than if it were to run its course. However, despite its failure to cure psychiatry managed to achieve legal and theoretical market dominance. Fringe developments such as the 'moral treatment' of the insane with its appeal to the use of kindness, encouragement, and self control faded because they were not easily amenable to professional claims to exclusivity and expertise (Scull 1979). If psychiatry had not succeeded in dominating the market, and defining mental distress as illness, the experiences of contemporary users might be rather different. To suffer severe mental illness is to present one's self as a legitimate object for the attentions of an army of mental health professionals.

Psychiatry's dominance was executed through its castles of power, the huge mental hospitals and their populations continued to grow until the middle of this century. Family 'carers' had little relevance at a time of institutional care. There was a long term solution to the problems of severe mental illness in the family, and lengthy hospitalisation was accepted, (often encouraged by the medical profession, supported by countless nursing and ancillary staff). In looking at the large hospital used by many of the users in the current study, one is struck first by its imposing buildings and size. Due for closure in one year (1997) its gardens, tennis courts, church, 'night-club', greenhouses and sports pavilion are falling into dereliction and neglect. In the first half of the century a prospective patient would have had all their medical, social and 'employment' needs attended to for their foreseeable future. The cost was a

submission to professional routine and the assumption of the role of mental patient, but the involvement of relatives needed only be minimal. This is not to suggest that relatives of people with mental ill health did not suffer emotionally through their loved one's problems but they did not play a focal role in what is professionally called continuing care. One can suggest that the caring role of relatives might logically have been limited to the period between the emergence of the 'problem' with its conceptualisation, diagnosis, and indefinite admission to hospital. The contemporary carer, however, has become the mainstay of continuing care. For people with repeated or non remitting severe mental illness, long stay hospital care is neither physically available, (hospitals are closing), nor an acceptable moral means of coping with users' needs. The difficulties faced by families no longer represent a traumatic period prior to the state assuming responsibility for the sick person, but the beginning of a way of life. Psychiatry's conceptual dominance has altered and been successively modified, but it remains in ascendance. The politicians and public are afraid, and psychiatrists control the medicines that can render these allegedly dangerous, unpredictable people safe. Safe but rarely cured.

Decarceration and Community Care

Perhaps the suggestion that community care is psychiatry with a new staff of unpaid, untrained 'nurses' seems unduly cynical. The rhetoric of community care and the logic behind the retraction (hospitals are not closed they are retracted) is presented politically as the rejection of institutional care and the provision of a better way of life for service users in more humane and homely surroundings.

On closer inspection the reasons behind the decline of institutional care appear complex, Turner suggests that the reasons included:

A wider interest in Freudian psychotherapy, especially among the middle class who came to reject the traditional 'warehouse approach' to the mentally disabled and disturbed. Secondly, there was a strong anti-psychiatry movement associated with the work of Szasz, Goffman and others which presented a critique of the asylum, drawing attention to the

negative effects of long-term incarceration and the low rates of recovery. Thirdly, there were improvements in anti-psychotic drugs which meant that patients could be treated outside the traditional asylum, (Turner, 1987:70).

People continue to be admitted to psychiatric wards but they do not remain there indefinitely (1987:71). Health purchasers emphasise the need for acute treatment, after which patients return to the community. Although there has been concern over low standards of care in some longstay hospitals which failed to treat patients with care and even subjected them to abuse, there has been a growing suspicion that some community based facilities are really 'institutions in the community'. Many new community residential and nursing homes have been built in the study area to house older people. They appear surprisingly large, able to take two hundred residents in some cases, but they have one fundamental characteristic which distinguishes them from the old hospitals - the cost of care is not borne by the NHS, but is means tested and defined as social or community care, for which the local authority or the user themselves pays.

The Legislation

'Community care' policy in mental health has been in operation at least since the hospital plan of 1962, but it has gathered momentum over the last decade. The Audit Commission report (1986) raised particular concerns over funding and the waste of public resources especially in relation to the care of older people. The populations using institutional care (those with a mental disability, the physically disabled and particularly older people) were increasingly provided for in residential accommodation, (very often at the expense of social security funding). Data illustrated an exponential increase in the cost to public finance and the Audit Commission queried whether many older people really needed such expensive and intensive provision. They suggested that gate keeping was required to make the most advantageous use of state resources. Older people could be assisted to stay in their own homes with domiciliary support, rather than receive 24 hour care in residential and nursing homes.

The Audit Commission suggested encouraging people to depend on their own resources.

The change to a community-based service thus involves much more than a change to the pattern of service provision. It involves a change of approach, with emphasis and priority placed on encouraging patients and clients to do as much for themselves as possible (Audit Commission, 1986:11).

While the flavour of the legislative literature at this time expressed the need for user independence and quality of life, there was a pressing concern over cost. This theme was developed in the Griffiths Report of 1988, and from this point onwards there is increasing emphasis on the role of carers in the context of relatives, friends and neighbours who provide (and had always provided) care for dependent members of the community. Griffiths viewed state support as filling in the gaps left where family and friends could not cope. There had been a fundamental shift in responsibility particularly in relation to older people but also in relation to other people who had traditionally received institutional care.

Publicly provided services constitute only a small part of the total care provided to people in need, families, friends, neighbours and other local people provide the majority of care in response to needs which they are uniquely well placed to identify and respond to. This will continue to be the primary means by which people are enabled to live normal lives in community settings. The proposals take as their starting point that this is as it should be, and that the first task of publically provided services is to support and where possible strengthen these networks of carers, consulting them about their needs and those of the people they are caring for, and tailoring the provision of extra services (if required) accordingly (Griffiths, 1988:5).

Griffiths painted a picture almost reminiscent of the television programme 'The Little House on the Prairie'. The intimate provision of care, provided selflessly by family, friends and neighbours. I do not question that many carers and

helped people provide and receive care altruistically, and prefer such private arrangements, but Griffith's analysis takes for granted the availability and willingness of carers. It assumes the existence of neighbours, family and friends, willing and able to provide such care in a time when there has been both a demographic decline in the availability of potential carers and a significant geographical mobility that has fractured community links and family networks.

This vision is even more problematic in the field of mental health. The current study suggests that not only are friends and neighbours unlikely to share in the provision of care but so are other close relatives. This confirms other work that suggests that when someone becomes the carer, others withdraw, as if they fear being asked to shoulder all the burden. Within the current study some parents did act as joint carers, but many carers were particularly critical of other relatives who would not even offer occasional help. The suggestion that a carer might have a night out while their acutely psychotic relative is supported by a neighbour or friend seems ludicrous.

The Community Care Act

The government's response to the Griffith's report was its white paper 'Caring for People' (Dept. of, Health, 1989). It reaffirms a commitment to 'providing the services and support which people who are affected by problems of ageing, mental illness, mental handicap or physical or sensory disability need to be able to live as independently as possible in their own homes, or in "homely" settings in the community' (1989:3). The paper emphasises the right of service users to influence decisions made about their care and advocates 'choice and independence' it also acknowledges that care is provided by

Friends, family and neighbours. The decision to take on a caring role is never an easy one. However, many people make that choice and its right that they should be able to play their part in looking after those close to them. But it must be recognised that carers need help and support if they are to continue to carry out their role; and many people

will not have carers readily available who can meet all their needs (1989:4).

The paper appears to give recognition to the role of carers and a commitment to supporting them. The proposals continue with emphasis on service flexibility, a market that is comprised of a range of providers and encouraging the development of good services at competitive prices. It is stated that 'assessment of care needs should always take account of the needs of caring family, friends and neighbours' (Dept. of Health, 1989:5). The paper appeared to set high standards for developing services that would match the needs of individuals (not categories of need) and would also support and enhance existing informal carer networks.

The proposed act appeared to favour promoting independence, value for public money and promised a change in the way services were structured that would lead to greater innovation and responsiveness to people's needs. The white paper proposed the adoption of care management as a tool to implement the new arrangements. Care management represented an advance from traditional social work practice where people had allegedly been assessed to fit service provision. In the past social services staff would visit someone to see if they could benefit from day or residential care, rather than consider the needs of an individual who might feel isolated, have mobility problems, and may also have a deterioration in short term memory.

A phrase frequently used at this time was of services being made 'more responsive' (Department of Health Social Services Inspectorate, 1992:9) to fit individual need. The Department of Health Social Services Inspectorate also spoke of

the empowerment of users and carers, instead of users and carers being subordinate to the wishes of service - providers, the roles will be progressively adjusted. In this way, users and carers will be enabled to exercise the same power as consumers of other services (1992:9).

Assessment was described as just one stage in the process of care management. From publishing information, the determination of the type of assessment needed, to the actual assessment, care planning, implementation, monitoring and review of the care package (1992:10). The white paper became the NHS and Community Care Act 1990 and was subsequently implemented in April 1993. Far reaching organisational changes took place within both health and social services creating purchasing and provider functions. Care management was introduced across the UK, though there were many forms that this took.

The implementation of the Act, occurred during the collection of data for the current study (this was conducted between 1992 and 1994) but continued contact has allowed data to be gathered since that time, up to 1997 when the thesis was completed. It has therefore been possible to gain an initial impression of the ways in which the Act has been implemented.

Care Programme Approach and the Mental Illness Specific Grant

The policy guidance entitled 'Community Care in the next decade and beyond' (Dept. of Health, 1990) recognised that additional arrangements would be needed to develop the services provided for mentally ill people in the community. Mentally ill people were regarded as having been a low priority for social services departments and the government proposed to fund a new ring fenced grant, the MISG (mental illness specific grant). This funding could be accessed by local authorities on application to the district health authority, and was for the provision of new services. It was granted initially for three years' though subsequently extended , and was the basis of many innovative projects.

The Care Programme Approach was also instigated at this time and discussed in the policy guidance. It was described as a 'systematic' procedure for the care planning of all people referred to the psychiatric services (Department of Health, 1990:76). It was stressed that it should not require additional resources but would make the care of mentally ill people in the community, or

awaiting discharge from hospital the subject of a well co-ordinated multi-disciplinary approach to the provision of after care.

Mental Health Legislation

Prior to and following the implementation of the NHS and Community Care Act people with severe mental illness could be made the subject of compulsory assessment and treatment in hospital. The Mental Health Act 1983 also required that multi-disciplinary after care be provided for people on discharge from hospital, but Section 117 only applied to patients detained for treatment under section 3 and under section 37 by the courts. Section 117 remains in force but its scope is limited, and there were doubtless many patients who needed after care, but were without the statutory right to provision prior to the implementation of the Care Programme Approach.

Practice under the Mental Health Act 1983 has been modified by the publication of the second code of practice in August 1993 and this gives clear guidance concerning the indications for using compulsory powers. In particular where there is evidence of severe persistent psychological harm to family, it reminds professionals that they do not have to live with the patient 24 hours a day (Dept. of Health, 1993:) and that their care plan should acknowledge this fact.

The Mental Patients in the Community Act 1995

The continued development of legislation concerning severely mentally ill people and those with community care needs may be seen to represent the fine tuning of the new arrangements advocated by community care policies, or it may simply be understood as a continued ad hoc response to the failure of these policies. The NHS and Community Care Act created a homogeneous user group, as consumers they were to be empowered to live in the community with the support services that they and their carers needed. The government, media and associated public opinion, however, have reacted with increasingly alarm towards severely mentally ill people.

Legislation and policy in relation to people with severe mental ill health represents a paradox. Somehow mentally ill people are to be recognised as worthy citizens and supported in living independently in the community (the Community Care Act), yet they are also seen as potentially disturbed, at risk of harm to themselves and potentially violent to others. Given these factors special provision is required to ensure that they are appropriately supervised (the Mental Health Act 1983 and the Mental Health Patients in the Community Act 1995). The numerous reports and enquiries speak of a small percentage of severely mentally ill people (eg Ritchie, 1994 and East London and the City Health Authority, 1995) who require more intensive after-care and supervision, for whom there might be associated involvement with the criminal justice system, homelessness and/or a refusal to comply with medication. There appears to be an attempt to separate the majority of severely mentally ill people from this sub-group, who allegedly present a risk to the public and to themselves, but actually making this distinction may prove difficult. Data from the current study suggests that many users had periods when they presented a danger to others or were at risk of self harm. Thus, rather than pertaining to a distinct sub group of severely mentally ill people, these characteristics were more commonly transitory aspects of the 'illness' that many users displayed. Some users were persistently aggressive or harmed themselves regularly, but these traits could often be identified more generally.

If the policy makers acknowledged the latter statement, the public might become even more alarmed and resistant to the resettlement of discharged ex-patients to the community or the creation of supported group living projects. The government has responded by the creation of supervised discharge orders under the Mental Patients in the Community Act 1995 but has not accepted the need for compulsory treatment orders for people living in the 'community'. There is a continued tension between the rhetoric of empowerment, user satisfaction and self determination, the public's perceived demands for protection from dangerously psychotic patients, and the resources needed to support these policies. Somewhere in a silent, unheralded fashion family carers play a significant role. Whether by government design or default, they provide cheap care and emotional support to users in the community, and can also alert professionals to aspects of risk. They are ideal, they are economical, and by involving them one can even claim allegiance to consumer empowerment.

Interpreting Policies and Legislation

It is easy to be critical of legislation and professional practice, and it is tempting to find something derogatory to write under the guise of being radical. This is not the intention and I will attempt to reflect excellence in practice and the more successful aspects of policy changes, as well as the difficulties elsewhere in the study. The data was gathered prior to the implementation of the Carers (services and recognition) Act 1995 and the Mental Patients in the Community Act 1995 (both implemented in April 1996). Therefore the main interviews cannot highlight the application of these changes. There is however reference to data acquired through my continued involvement as a carer of someone using services, through practising as a mental health worker, through contact with colleagues, and discussion with carers and users in the voluntary sector. Recognising that the use of such data extends beyond the traditional boundaries of data collection, I assert that the information gathered is treated critically in terms of its representatives and generalisability. (To cut off from

such pickings would be to return to a false positivistic position and ignore valuable material).

Although the NHS and Community Care Act 1990 became law in 1991 it was not actually implemented until April 1993. From data collected through the current study it was apparent that there was no 'big bang'. Users and family carers were unaware of any profound changes taking place. In the early months no-one commented on the consequences of the changes, of any improvement or deterioration in the care they received. Carers were aware in some cases, however, of departmental re-organisations that had direct consequences for them. These usually meant losing a familiar worker and having to wait 'until restructuring was over' before their case could be reallocated. If you had no worker this process involved waiting weeks, often months to be allocated. Carers did not appear aware of the purpose of such exercises nor of any improvement that followed. Many were veterans of past re-organisations. The policy changes were required to be in place by April 1993 but the impact has happened more gradually.

By 1995, during the analysis of the formal interviews, it was clear from my contacts that the impact of change was being felt, at least by service users. The data seems to reflect the actual pace of change in practice and alteration to departmental structures. These changes were most marked in social services departments, as they took on the role of identifying social care need, making assessments and reviewing the services provided. However the health service also altered, with the creation of purchasers or commissioners, trusts and GP fundholders, everyone went into business and began to produce colour brochures.

Social policy analysts have tried to deconstruct the legislation, to put it in a historical context, and to look for inexplicit policies and consequences. Levick notes that the brokerage approach to social care was not new and had been suggested in the Barclay Report of 1982.

However its insertion in a 'mixed economy' of welfare is a departure from current social work practice. Case management models are various in conception as a response to the inter-related problems of service fragmentation, poor or non existent resource targeting, co-ordination and control; and the difficulty of productively interweaving statutory and informal care' (Levick, 1992:82).

As previously discussed, the policy of care in the community was not a new development, and had been supported by Labour governments as well as by the Conservative party. Chapman et al (1991:5) observe that governments have advocated community care since the late 1950s. The particular route taken by the Thatcher government reflected her commitment to 'housekeeping' which she applied to the nation. There was a great deal of talk about waste. Health care, education and other public services had always been financed centrally. The public employee could apparently dip into the deep pockets of County Hall or the Health Service without any sense of financial responsibility. At the same time the bill for the support of older people needing residential care had grown exponentially. Any one could access residential care, and if one had no savings the state paid. Social workers who might be involved had no concern over the appropriate use of state funds (from the DSS) when placing an older person in a residential home. Their concerns were conceptualised in professional terms: user choice, independence and also risk. They had the freedom to concentrate on the welfare of the individual, rather than consider the total budget available for groups of people.

It will never be clear if the government of the day made a conscious decision to tighten the welfare state's belt. It has been said policy decisions are more likely to emerge from a complex interplay of interest and the intervention of unforeseen circumstances. However the Audit Commission report 1986 did alert the government to 'perverse incentives' in the system (1986:43) and with concern over a growing population of older people, with its inherent social and health needs related to dementia, there was an urgent need for action. It

seems difficult to imagine that financial concerns were not paramount in determining the timing, and nature of the response. So many older people had significant capital tied up in their homes, this could be liquidated and would help pay towards the costs of residential care. The government had great faith in managerialism (Chapman et al, 1991) as the rational science charged to administer the distribution of welfare resources. Chapman et al. observe that although the Community Care Act proposes much greater user participation and choice, financial concerns are only thinly concealed.

Ostensibly, the image of more efficient and effective provision, and increased consumer autonomy, as a feature of new right market liberalism may have some appeal. On closer analysis, however, the latent functions of many of the proposals and policies for community care are tarnished by ideological and economic considerations, which run counter to many ethical and humanitarian principles generally associated with social welfare. The language of 'privatisation', cost effectiveness, and value for money is replacing notions of the needs and rights of individuals. The 'business culture' which increasingly drives the management of health and social services has led to preoccupation with 'image' and 'presentation' not formerly considered important in the public sector (Chapman et al, 1991:12-13).

I have quoted at length from Chapman et al. They seem to convey the flavour of welfare provision at the present time. Some writers still talk in radical terms about anti-psychiatry. Perhaps it is time for a radical response to managerialism. The professionals have apparently had their day, the managers are everywhere. They are now within each 'profession', within every aspect of service planning and provision, asserting a set of common managerial values. These values offer a specious consumer autonomy but do we really want the quality on our health and social care assessed, rated and packaged like a fast food burger? It is an analogy I choose, because the quality of burgers and fast food is measured carefully. Standards are set pertaining to price, choice and speed of service, but the food often tastes

insipid. It seems that quality is being sought after and measured as never before, but the measures chosen appear distant from more complex indices of user satisfaction. Although the Griffiths report talked of 'optimal quality of life' (Chapman et al, 1991:13) the managerialist focus appears to be around response rates, through put etc. Changes in the assessment and provision of social care mirror the changes in the NHS. Hunter noted there was concern to rationalise a health system dominated by individual professional style. The differing prescribing habits, surgery procedures and clinical orientation of specialists throughout the country revealed itself in differing outcomes, survival rates from cancer, waiting times for impatient surgery etc. Some doctors prescribed much more cheaply than others. Hunter (1994:13) observed that the new era in the NHS put professionals within a system of accountability. Limits were placed on prescribing costs and clinical practice subjected to medical audit. Comparisons were made between hospitals according to performance criteria and league tables devised.

Although it was initially claimed that consumers would be able to influence the system, by creating a reduction in demand for poorer quality services, this vision has proved naive. Health managers will tell one without any hesitation that their customers are the purchasers: health commissioners and the GP fund-holders. Patients merely use the services, they do not buy them. In reality users of health and social care are pawns in provision that is negotiated on their behalf through block contracts. One wonders what revolution in service quality might be created should users of mental health services, both social and health, be given 'vouchers' or 'cheques' to purchase their own care? Mental health care users in the current study, and by proxy their families, never spoke of feeling the dignity of being customers. On the contrary, the carers spoke of a service that made them feel as though their relatives were prison inmates and that they were visiting a jail.

In the Summer of 1996, legislation was enacted to permit local authorities to pay users directly, to buy their own community care services. These so called 'direct payments' had previously been deemed illegal (Morris, 1994:25). Morris

observes that the Community Care Act does not foster an independent life style for disabled people, but considers them in need of help, such help should be provided by professionals. Professionals must also decide how much and what form such support should take. In this sense disabled people are not seen as adults, able to control their own circumstances, but as needing care.

'Care' - whether it refers to people giving paid or unpaid help - does not mean to 'care about' someone in the sense of loving them. Rather it means to 'care for' someone, in the sense of taking responsibility for them taking charge of them (Morris, 1994:26).

Disabled people, in the sense used by Morris, are people with a physical impairment who are disabled by a society which fails to grant them equal opportunities. It is anticipated that direct payments will only be offered to certain categories of people, probably the physically disabled and not those with severe mental illness. Disabled people, in Morris' work, experienced a real sense of control over their circumstances. Through using payments provided by the defunct Independent Living Fund, they were able to employ support workers themselves. This process would seem to reflect the spirit that community care claims to aspire to. The consequences of direct payments are far reaching. There is already considerable concern over the under-funding of community care. The Disability Living Allowance is paid to all who 'qualify' by completing an application (the form is usually countersigned by professionals) and people with severe mental illness can also apply. The subjective impression one gains by talking to users and professionals however, is that DLA has become harder to obtain. People feel that its budget is over-stretched and that many people with genuine needs are now being turned down.

Community care policy and practice appears to focus on the allocation of scarce resources. Each financial year the available funds are allegedly more limited and local authorities face difficult decisions about which services to cut, which workers to make redundant and how to negotiate adequate quality services for the least money. There is a fine dividing line between achieving

optimal value for public money and providing or contracting for inferior quality services.

Ring fenced grants have cushioned the impact of this process for severely mentally ill people. The MISG and its successor the Special Transitional Grant are however time limited. There is an impression gained through anecdotal data in this study that resources are now under severe strain. (Funds were more liberally available in the early months, after implementation of the Community Care Act.) Managers are now having to be more cautious about releasing resources and this is leading to a professional suspicion that people who have significant community care needs are now defined as below the eligibility criteria.

This situation is aptly described by mental health users in a local independent magazine. They note that the function of trained social workers is now one of financial gatekeeper.

The trained social worker has become an administrative technician, assessing needs and matching to the available budget. Care as such has become delegated to a legion of care providers social work has become a managed service ... Social workers have become experts at telling you what you can not have even when supported by an assessment. In many ways it has become a paper chase, recording all the meetings that in the end lead nowhere (The Boat on the Tyne, 1996:1).

The Legacy of the Community Care Act

Literature dated 1992 already appears passé in this debate. It is dated by the wisdom of hindsight, because we know that the promises are being broken. For example 'involving users/carers from the outset is a means of setting the tone of partnership which should characterise the whole process' (Department of Health SS1 1992:39a). 'The basic principle is to bring the decision making as near to the user as possible' (Department of Health, 1992b:17). Such

statements permeate the rhetoric of the act and its guidance material. Taylor et al, (1992) note that the Act emphasises 'the empowerment of users and carers as an explicit goal' (1992:28) and remarks on assessing the carer's willingness and ability to carry out care provision (1992:29). There are also ambitious recommendations that users, carers and other stake holders be involved in agreeing service specifications, and be engaged in training professionals (1992:31-32).

It might be argued that a vociferous expression of resentment or complaints by user organisations illustrate the success of consumer empowerment. People one could say, have become aware of their possible entitlement and expect public services to be accountable. I could find scant evidence to illustrate that the spirit of the Community Care Act was in force. The reality appears to be an emphasis on a managerialist approach and a preoccupation with financial restraints. Devolving budgets may have led to greater financial awareness amongst basic grade professionals and their managers, but it has had the effect of making professionals protective, and anxious to define a problem as pertaining to the responsibility of another agency or team. Paper work has escalated, a parody of the sensitivity and responsiveness people experiencing difficulties actually welcome. Users (and carers) have not become real customers with associated influence, and agencies which once campaigned and acted independently are now contracted to provide services. They must now dance to the commissioners' tunes.

In re-assessing the position of carers of people with severe mental illness, one must place their experiences in this policy context. Although the term carers appeared frequently in the early documentation, services for carers may be seen as an inevitable early casualty in the battle for resources. It could be reasonably argued, that the burden of care in the community rests more heavily on carers' shoulders than ever before.

chapter three

Definitions, Treatments and Causality Theories in Severe Mental Illness:

Their Consequences for Carers

In this chapter I discuss the literature which defines the criteria for diagnosing severe mental illness. I review theories of causality and examine the prevalence of severe mental health problems. This leads inevitably to a discussion of the 'medical model' of mental illness, and to alternative theories which were particularly influential in the 1960s and 70s. This discussion provides the context for carers' experiences, not only of 'mental illness', whatever we conceive it to be, but also their relationships with professionals.

The research has attempted to explore the experience of people supporting adults with *severe* mental health problems. This involved the creation of boundaries and criteria for selecting the sample. Recognising the problems inherent in the medical model, and allowing for the fact that diagnoses are socially constructed, I chose to talk to carers of people with schizophrenia and manic depression (often called bipolar disorder). In order to reach carers of people outside of the psychiatric system I also included families of people who clearly displayed signs and symptoms that fulfilled standard diagnostic criteria for these disorders. Given my experience I felt competent to apply these criteria as defined within the DSM IV (fourth edition of the diagnostic and statistical manual of the American Psychiatric Association).

The literature defining schizophrenia and bipolar disorder is predominantly medical. It is written from a positivist standpoint which accepts the reality of mental illnesses as a given fact. The task for psychiatry is to investigate anomalies in epidemiology and to compare the efficiency of a range of treatment regimes. Literature which can be located within a sociological framework or that written by so called radicals (ie anti psychiatry) challenge the very basis of the medical model. The user movement has also been vociferous in offering new interpretations of experiences traditionally regarded as pathological. It is my opinion that none of these approaches is satisfactory from the point of view of carers. While users are at last being offered the opportunity to define their experiences for themselves this right has yet to be extended to family supporters.

Defining Severe Mental Illness

Schizophrenia and bipolar disorder have been considered to be functional illnesses. By functional it is meant that the disorder has no demonstrable pathology (but Gelder et al (1993) note that it does not mean there is none). Wing and Wing title their book on schizophrenia and manic depression 'psychoses of uncertain aetiology' which more accurately conveys the current theoretical position (Wing and Wing, 1992). In electing to focus on functional psychoses I have chosen to ignore the organic states which are associated for a range of syndromes but can be viewed as distinct in that they are understood as disease processes and less likely to attract stigma.

It is probably insouciant to refer to manic depression as a psychosis. The term 'psychosis' tends to be used when there are signs and symptoms qualitatively different to those experienced by 'normal' people. Hence the term 'psychotic' is usually applied in the presence of delusions and hallucinations or when insight is lacking. In manic depression there may be an acute manic period where the client experiences such changes (Carlson and Goodwin, 1973) but this is

usually transitory. Depression may also include psychotic features (American Psychiatric Association, 1994:187). On close inspection the distinction between psychotic and non-psychotic features blurs as the shame and guilt of depression merges into the conviction of having committed an unspeakable, imaginary crime. The term psychotic continues to be widely used however, both professionally and in the media.

Diagnosis is the prerogative of the medical profession (Jones, 1988:14) and only they have the legal power to bestow and withdraw a diagnostic label (less erudite labels such as 'mad' are bestowed by lay people). Some people in the sample have not been subject to medical scrutiny for long enough to receive such a label, but have been included where their symptoms are prominent in order to portray the experiences of their carers. Ordinary people categorise particular difficulties in terms of mental illness and feel competent to do so and case law recognises this phenomenon (Jones, 1990:14). Bleuler first used the term 'schizophrenia' earlier this century, as he felt that the splitting of mental functions was central to the problem (Gelder et al, 1993). Schizophrenia is described primarily as a disorder of thought (Newton, 1990:90) but its effects are felt throughout the individual's personality. According to traditional psychiatry

it is described as a psychosis, which is characterised by a distortion in the person's perception of reality. In psychotic disorder, thinking, emotions, attention and communication can be affected, seriously interfering with the person's ability to function in a way which might be considered normal (Newton, 1990:90).

Gelder et al (1993:268) note that schizophrenia defies accurate description because the concept has been used in very different ways. This has made comparison of treatments and studies of prevalence and prognosis difficult to evaluate. The concept of schizophrenia was applied more widely in the US

than in the UK (Gelder et al, 1993:280). The International Pilot Study of Schizophrenia conducted in 1983, drew attention to core signs and symptoms recognised across a range of countries (Gelder et al, 1993:280) as indicative of a diagnosis of schizophrenia. This has led to a more reliable approach to diagnosis.

Indicative signs and symptoms are listed to aid recognition and reliability. The DSM IV refers to the diagnostic and statistical criteria of the American Psychiatric Association (American Psychiatric Association, 1994). Without suggesting aetiology or prognosis the DSM sets out strict criteria on which to base a diagnosis and permits the comparison of cases. These include the range of signs and symptoms, their severity, duration and differential diagnoses. The system is multi-axial and also takes account of physical disorder, personality and contextual stressors.

Commonly experienced core symptoms of schizophrenia include holding delusions. A delusion is a belief that is firmly held even in resistance to contradictory evidence, 'and is not a conventional belief, such as that person might be expected to hold, given his educational and cultural background' (Gelder et al, 1993:13). A very common experience held to be of diagnostic significance is experiencing auditory hallucinations which consist of voices talking about the person (Leff, 1982:11). Some people, however, experience hallucinations of other sensors, including touch or smell (Barrowclough and Tarrier, 1992:5). Jenner et al (1993) draw attention to the fact that many so called 'normal' people hear voices and are not felt to be mentally ill. There are clearly other processes at work that comprise the labelling and treatment of the mentally ill. They also note that even symptoms identified by Schneider as being of first rank significance in the diagnosis of schizophrenia are found in people suffering other mental illnesses (Jenner et al, 1993:69). In conclusion there are no definitive tests or signs of schizophrenia and it defies recognition at the present time, except by clinical examination of the mental state.

'For the moment, therefore, the main basis for delimitating the group of schizophrenias must remain operational' (Stromgren, 1982).

If schizophrenia is not a discrete phenomenon why give added credence to the illusion? Schizophrenia is a category that can be used to describe severe mental suffering. Though its use has been associated with stigma it can also be a focal point for mobilising resources. Sedgewick argued that elegant literary semantics had encouraged the belief that mental illness did not exist except as a vehicle of social control (Sedgewick, 1982). This he felt had disempowered people with mental illhealth.

While some may recognise the florid or acute signs of schizophrenia such as hearing voices, feeling that people can hear one's thoughts, or that people are inserting ideas into one's mind (Leff, 1982:10-11), many are less conscious of the impact of disabling 'negative symptoms'. These include 'under-activity, lack of drive, social withdrawal, and emotional apathy' (Gelder et al, 1993:272). Though superficially less threatening than the acute features, persistent negative symptoms are demoralising, exhausting and for the onlooker or carer they can become irritating. The sufferer from these problems may appear dirty, dishevelled and lazy.

Many people with schizophrenia also suffer depression (Gelder et al, 1993:274) which may be a consequence of long term treatment with anti-psychotic medication, or a response to the destructive impact of the illness. It also seems likely that people with schizophrenia are also subject to primary depression and this may result in self harm.

Another characteristic of schizophrenia is the frequency of a lack of insight, especially during the acute phase. The World Health Organisation study listed the most commonly occurring symptoms and found that 97% lacked insight

(Gelder et al, 1993:272). This last fact has profound implications as it means that most sufferers must rely on the judgement of others when accepting treatment. Many will do so very reluctantly and for others compulsory treatment compounds their alienation and suspicion of the world around them.

Prevalence

Schizophrenia is a relatively common disorder with a lifetime risk of around 0.8% (Gelder et al, 1993:269). It is said to occur at the same rate the world over. I have found no mention of a difference in the rates between the sexes, but Foerester et al. suggest that some men may form a sub-group. Unlike the women, these men showed abnormalities of behaviour while still children. Foerester et al. question whether this might be linked to neurological trauma (Foerester et al, 1991:171). Figures can mask important variations in susceptibility and Torrey (1983:196) notes that 'even in the United States there are variations in schizophrenia's distribution, with an especially high concentration of it amongst the poor people and the inner-city'. The 'epidemic' of schizophrenia amongst Afro Caribbean people living in the UK has also forced attention on its distribution and on the social forces that this implies (Lewis et al, 1990:410). As with other (physical) illness (Townsend and Davidson, 1982) it appears that those disadvantaged socially are also disadvantaged psychiatrically.

Treatment

The main treatment for schizophrenia remains pharmacotherapy and essentially treatment with anti-psychotic medication. Early enthusiasm over the impact of anti-psychotics such as Chlorpromazine, which was introduced in the 1950s, has been tempered. A perceptive user of depot anti-psychotic medication has described the tools of psychiatry as “blunt instruments”. Anti-psychotic medication is commonly used to control ‘disturbed patients whatever the underlying psychopathology, which may be brain damage, mania, toxic delirium, agitated depression or acute behavioural disturbance’ (BNF, 1992:139). Anti-psychotic drugs are believed to act by blocking the dopamine receptors (BNF, 1992), but they affect a much wider range of systems and consequently are associated with unwanted side effects (Gelder et al, 1993:647). Though the drugs may be successful in the management of the acute syndrome or positive symptoms, feelings of apathy and depression are less responsive to such treatment (Gelder et al, 1993). Medication becomes a central feature of the lives of severely mentally ill people and their carers. The relationship is essentially ambivalent and users may find themselves ever juggling the advantages and disadvantages of compliance. For many, at least for a period, compliance is legally enforced. A fuller discussion of carers and medication is given later.

There have been recent developments in drug treatment with the use of new anti-psychotics such as Clozapine. This drug has been licensed for the treatment of drug resistant schizophrenia. It is said to help people ‘become less withdrawn and apathetic’, and has been associated with less movement disorder than traditional drugs (Sandoz, date not supplied). There are new drugs developed regularly but research in this area reflects the priorities of drug companies which may not be synonymous with those who use the medicines.

Cognitive Therapy of Schizophrenia

There have been some positive approaches to treatment such as the provision of cognitive therapy. This has been used to teach people experiencing auditory hallucinations to reattribute these to internal processes rather than to external agents (Haddock et al, 1993). Kingdon and Turkington (1991a) have encouraged the recognition that auditory hallucinations form part of a continuum of experience and therefore do not differ *qualitatively* from 'normal' mental events. These approaches mark an advance especially as not all subjects respond to drug therapy. They also engage the patient in collaborating in their treatment as cognitive therapy involves the client as an active participant in their care (Beck et al, 1979). Traditional approaches have tended to treat the schizophrenia sufferer as beyond reason. Slater and Robb, in 1969, illustrate this approach and stated that 'it is a waste of time to argue with a paranoid patient about his delusions' (Kingdon and Turkington, 1991b:101). The wider use of cognitive therapy could prove empowering for clients as well as being an effective treatment. Cognitive psychiatry emphasises psychotic ideation and experience as distortions of ordinary thoughts and feeling. Fowler et al suggest that it may be useful to think of frank psychosis as a more severe manifestation of some of the abnormalities in belief, thought and experience that may affect many normal people at some time or another (Fowler et al, 1995:39). They add that through adopting this approach stigma could be reduced significantly as people with psychosis have traditionally been regarded as distinct from 'ordinary' people. For the majority of users however, these approaches are not widely available. Most sufferers must accept, albeit reluctantly, that the only treatment available for them will be anti-psychotic medication, either in the form of tablets or by depot injection. By proxy their carers have to accept this fact too. At present cognitive therapy is more common in teaching departments and not routinely offered.

The Course of Schizophrenia

Although people may suffer from short periods of disturbance the term schizophrenia tends to be reserved for periods of prolonged and/or repeated illness. This process reinforces the pessimism and stigma associated with the label. Indeed, the DSM IV specifies that the symptoms must be present for at least six months, and that florid signs be recognisable for at least a month (American Psychiatric Association, 1994:48). Transient periods of 'psychosis' that might be attributable to the use of drugs or to environmental stressors receive recognition under labels such as 'brief psychotic disorder'.

It follows that providing a diagnosis of schizophrenia implies a statement about the prognosis. The prognosis is widely accepted as dividing into thirds. Stephens reviewed 25 studies that followed people diagnosed with schizophrenia for an average of ten years (Torrey, 1983:65). An assessment was made as to whether people were 'recovered', ie symptom free; 'improved' (some symptoms and the possibility of occasional hospital care); or 'unimproved'. The studies examined the outcome for over 4000 people. Depending on the types of patient included the prognosis varied. On average however, around one-third 'of all patients hospitalised and diagnosed with schizophrenia will be found to be completely recovered when followed up ten years later. At the other end of the spectrum the number of patients rated as "unimproved" at the end of ten years averaged 44 per cent' (Torrey, 1983:66). The author does stress that the studies include people with the most severe symptoms and concludes that the figure is a pessimistic estimate. Schizophrenia remains an unpredictable disorder and although some people remain well for many years the majority face episodic or persistent difficulties. Given that the disorder has an early onset (Goodwin and Guzes, 1989:46) it often leads to many years of suffering and handicap.

Warner queries the inevitability of the negative outcome that the majority face, and advocates a change in diagnostic practice that would include people with brief or more favourable variations of the disorder. He believes that even before the development of anti psychotic medication data suggest that many people did recover and returned to leading full lives (Warner, 1994:58). Unfortunately as Warner recognises, schizophrenia is a label which is applied increasingly at a point where the physician has given up all hope of the patient having any quality of life. Given this practice it has become a self fulfilling prophecy.

Bipolar Disorder

There appears to be less written about bipolar disorder and it lacks the coverage given to schizophrenia by the press. Bipolar disorder is the favoured term for what is colloquially and technically referred to as manic depression. It is the expression used in the DSM IV (APA, 1994) and is gaining popularity. The study focuses on schizophrenia and bipolar disorder as there is evidence suggesting that both disorders rather than schizophrenia alone are associated with a high degree of disability (see Huckle, 1993). Material reviewed by Goldberg and Huxley note that people treated in the community alone rather than in hospital tend to have so called mild mental illness.

In general terms the former comprise depressive illnesses and anxiety-related disorders, while the latter contain a substantial proportion of more severe illnesses, such as organic mental disorders, schizophrenia and bipolar affective disorders. Such illnesses are associated with much greater social disability and are much less likely to resolve spontaneously with time (Goldberg and Huxley, 1992:5).

Goldberg and Huxley (1992) also draw attention to the fact that so called 'mild' mental health problems can also cause considerable suffering. The decision to focus on schizophrenia and bipolar disorder is not intended to trivialise the experiences of those who are dismissively referred to as the 'worried well'.

Attempts to distinguish between schizophrenia and bipolar disorder refer to the latter as a primary disorder of mood. People suffering bipolar disorder are thought to experience an exaggerated spectrum of affect usually including severe depression and periods of marked elation. While unipolar affective disorder of the depressive form is a relatively common psychiatric disorder, the bipolar form occurs less frequently.

Depression

Brown and Harris (1978) note that there is no clear dividing line above which depressive feelings become 'clinical' or worthy of psychiatric recognition. There appears to be a continuum where understandable feelings of sadness merge with a clinical syndrome. Depression is associated with 'depressed mood, pessimistic thinking, lack of enjoyment, reduced energy and slowness' (Gelder et al, 1993:217). Some individuals show 'psycho-motor retardation' where they think, speak, and move slowly (Gelder et al, 1993:218). Other features noted by the DSM IV for a diagnosis of major depression are hypo- or hyper-somnia, appetite disturbance, and a lack of interest in things that are normally valued by the client (APA, 1994). Last, but most significantly, are suicidal thoughts. In a mildly depressed person the thoughts may reflect a perceived futility and hopelessness, but a severely depressed person may come to be constantly preoccupied with thoughts of suicide (Gelder et al, 1993). This means that for a significant minority bipolar disorder becomes a fatal illness.

Mania

Like the term depression the word mania has entered common usage but it is rarely applied with accuracy. During periods of mania the client's behaviour may comprise the extreme opposite to depression. This phase is characterised by elation, overactivity, and a reduced need for sleep. Manic people can experience pressure of speech and may jump from subject to subject (Gelder et al, 1993:223). Though manic people can be entertaining (in small doses) others display manic excitement through irritability 'and this irritability can easily turn to anger' (Gelder et al, 1993:223). In a study of the phases of manic episodes in 20 patients, Carlson and Goodwin (1983) noted that the episode was initially typified by being happy, talkative, and overactive. As the patient's mania exacerbated they could be suspicious and grandiose. Some individuals reached a peak where behaviour was severely disturbed. At this stage the patient was often deluded, might experience hallucinations, was angry, occasionally incontinent and clearly unable to think rationally. Sufferers are often also profoundly *unhappy*. The descent to normality, with or without medication, follows the same stages experienced in the exacerbatory phase, but the time this takes varies widely between individuals. Some individuals might return to normality over a period of months or weeks, for others the transition from depression to mania and back can occur over hours (Carlson and Goodwin, 1983).

Mixed Affective States

Clients typically experience more periods of depression than mania, and may only experience one manic episode. Some people do not experience the classical highs and lows with periods of normality interspersed. They may show symptoms of mania and depression together, or may move from one exaggerated state to another, without any intervening period of normal mood.

This presentation is referred to as a 'mixed affective state' (Gelder et al, 1993:225).

The bipolar model, which suggests that mania and depression represent opposite ends of an affective continuum, appears flawed when subjected to closer inspection. If one may experience overactivity, grandiosity and be suicidal at the same time the conditions cannot be mutually exclusive. Differing causal mechanisms may underly the basis of manic and depressive symptoms or they may both simply represent disturbance of affect.

Mixed states were recognised by Kraepelin at the turn of the Century, but more recent work has noted that people in mania quite commonly experience periods of depression (Gibbons, 1982b:iii). 'American authors speak of mixed states when patients satisfy criteria for the diagnosis of mania and depression during a single episode of illness. Himmelhoch, Mulla and New reported that the first episode of affective illness was mixed in this sense in 31 per cent of 84 bipolar patients' (Gibbons, 1982a:iii). The term 'mixed state' is used in DSM IV. Gibbons notes that such individuals had usually suffered periods of mania and 'pure' depression before the mixed episode and this aided in diagnosis (1982b).

Bipolar disorder can constitute a complex syndrome where mood fluctuates from 'ecstasy to despair' (Gibbons, 1982a:iii). Although mildly manic people may feel very happy, the more severe episodes are traumatic for sufferers and onlookers alike. Murphy and Beigel noted that 'mania appears to be not as well characterised by elation but rather by a state of heightened overall activation with enhanced affective expression together with liability of affect' (Gibbons, 1982b:100). This latter observation endorses my own experience of trying to cope with someone who would move from suicidal despair and then to rage and back over the space of half an hour. We were frequently left shocked

and bewildered by the force of the emotional turmoil, most of which had inevitably receded by the time the doctor arrived.

Schizo Affective Disorder

Clinical experience inevitably diverges from text book descriptions, and people present complicated and irritatingly incomplete diagnostic pictures. Some people report being diagnosed with schizophrenia, then as bipolar with a final return to a schizophrenic label. (Users have coined the phrase 'psychiatrist dependent diagnosis'). Torrey notes that 'many patients have symptoms which place them somewhere on a spectrum between schizophrenia and manic depressive illness. Most psychiatrists have seen individual patients who fit only one of these disease entities perfectly, but most have also seen patients with a confusing melange of symptoms of both diseases' (Torrey, 1983:53). The DSM IV permits a diagnosis of schizo affective disorder (APA, 1994). In such cases the criteria for both disorders are met, and treatment is often a serendipitous cocktail of medication used for the treatment of both disorders.

Prevalence

Torrey (1983) notes that bipolar disorder occurs less frequently than schizophrenia and occurs (is diagnosed?) more frequently in people of a higher socio economic status. The disordered behaviour of manic people usually leads to contact with the specialist psychiatric services or the police but Gelder et al (1993) note that estimates are imprecise. It is believed that the life time risk is under 1% (1993:236). Williams suggests 0.5% prevalence (1992:7). The allegedly higher rate for women follows the figures for unipolar depression where women show a rate two to three times that for men (Milligan and Clare, 1994), but other authors suggest no gender difference at all.

Course of Bipolar Disorder

Bipolar disorder, though a severe mental illness, has traditionally been afforded a more positive prognosis than schizophrenia. Some regard it as the illness of the talented and famous. As Torrey writes, 'many highly responsible and successful people have suffered from manic depressive illness but have been able to pursue their careers between episodes of illness' (Torrey, 1983:52). Huckle feels that the traditional view of the prognosis was overly optimistic and notes that two-thirds to three-quarters of people admitted with mania will require re-admission on at least one occasion (Huckle, 1993:10). Not everyone experiences a complete remission of symptoms between acute episodes and some experience rapid cycling (defined as four or more cycles in a period of twelve months (APA, 1994)). Others suffer mood changes several times per week - the 'ultra'-rapid-cyclers.

Textbook accounts of the illness can underplay the effect that repeated periods of manic activity and misery can have on the sufferer and their family. Hyperactivity during the manic phase will lead the sufferer to do and say things that may have lasting and destructive consequences. Carlson and Goodwin (1983) document the presence of paranoia and hypersexuality. Kraepelin observed that the patient can be 'dissatisfied, intolerant, fault finding' (Huckle, 1993:10) and that 'when he comes up against opposition to his wishes and inclinations, trifling external occasions may bring about violent outbursts of rage' (Huckle, 1993:10). When the mania passes, the sufferer may have to face the chaos that they have inadvertently caused. This may include tackling debts incurred and trying to heal relationships damaged by inappropriate sexual activity and drunkenness. Vulnerability to relapse may often be a factor in the decision of people with bipolar disorder and schizophrenia to commit suicide. Carr notes that psychotic suicide, in response to delusions or hallucinations, is actually rare, and that suicide tends to be contemplated

during intervening periods, when patients despair about the future (Carr, 1993:2).

Treatment

Though mild depression can be safely treated in the community manic behaviour and severe depression require 24 hour care. In severe depression the sufferer may be immobile, unwilling to eat or care for themselves, irritable and actively suicidal. During a manic phase they exhaust their families by their overactivity, extravagance and offensive comments. In addition the manic person usually lacks insight (Gelder et al, 1993:224) and pours scorn on the attempts of others when they frustrate his or her plans. For this reason treatment is often enforced under the Mental Health Act 1983.

Depressive episodes are treated with anti-depressants or ECT, but medical enthusiasm is tempered by the risk of potentiating a further episode of mania. During an acute phase of overactivity and where there are psychotic symptoms, mania is treated with anti-psychotic medication. The prophylactic treatment of mania is achieved through the use of Lithium Salts (Gelder et al, 1993:667). Though Lithium is toxic in excess it is highly successful in the treatment of mania. People who do not respond to Lithium may be treated with other mood stabilisers, such as Carbamazepine or Sodium Valporate. The success of treatment depends not only on the response to medication, but also on compliance. Huckle notes that non compliance is common, and that 75% of relapses are believed to be due to non compliance (Huckle, 1993:11). Typically the decision to comply with medication (especially when it causes side effects, and when one feels well,) causes difficulty for sufferers and to the people who support them.

Cognitive Therapy of Bipolar Disorder

Cognitive therapy has achieved wide recognition of its success in treating depression and there are a number of studies illustrating its success (Scott, 1982). It has a favourable outcome when it is compared to standard antidepressant medication and this makes it particularly useful for people who suffer side effects of medication or whose depressive symptoms do not respond to drugs. Cognitive therapy of depression derives from Beck's observations of the views held by depressed people, and of the logical errors that can be observed in their thinking patterns. The depressed person is typically pessimistic about the world, their own abilities, and about their future (Beck, 1979). Therapy is based on training the sufferer to recognise their logical errors and depressogenic assumptions. Beck believes that depressed mood is the result, not the cause of depressive thinking (Beck, 1979). If the client can challenge depressive thinking they can prevent episodes occurring in the future.

Cognitive therapy has much to offer, not least in its emphasis on empowerment and self responsibility. Scott emphasises that it was not envisaged as appropriate for 'organic' depressions and bipolar states which were believed to require standard physical treatment (1984). Williams (1992:69) however, felt that cognitive therapy had not proved ineffective with 'bipolar depressives, highly regressed patients' and those with psychotic symptoms and that it could usefully be tried. Scott is now modifying her theory and anticipates using cognitive therapy for people thought to have 'biological' mood disorders in the near future.

Many people with mood disorders might benefit from acquiring cognitive skills, if only to supplement their own coping mechanisms and other treatments. Cognitive therapy for mania in an acute phase appears unrealistic due to the

overactivity, lack of insight and risk of aggression, but cognitive skills taught during remission could empower the sufferer and help them exercise control. Of course, cognitive therapy cannot change the client's environment if it is actually highly 'depressogenic'.

Alternative Therapy

Users may seek alternatives to drug treatment such as meditation, aromatherapy or homeopathy. It feels vital that clients be offered a choice and access to such therapies if they prove useful. Help should be free from professional ridicule and financial exploitation. These treatments are not freely available to most patients, especially the poor or inarticulate. Given their limited employment prospects people with schizophrenia and manic depression are unlikely to be able to afford to access alternatives and are forced to rely wholly on medication.

Symptoms that Mimic Schizophrenia and Bipolar Affective Disorder

Schizophrenic type symptoms may also occur in association with the use of prescribed or illicit drugs. Confusion may arise when individuals who may have been vulnerable to developing delusional ideas also use illicit drugs. Such people may be perceived as being responsible for their symptoms, and this can have consequences for access to appropriate services, affecting the potential patient and those supporting him or her. Gelder et al (1993:550) observe that the evidence to support a belief that using cannabis can lead to psychosis is inadequate. People drinking alcohol to excess may experience threatening auditory hallucinations in the presence of clear consciousness, and amphetamine users can develop symptoms akin to schizophrenia with persecutory delusions (Gelder et al, 1993). Help for people with drug *and* mental health problems is currently inadequate with professionals compartmentalising people's needs and ignoring co-existing difficulties.

It is quickly apparent that diagnosis rests on complicated processes and is not purely a rational scientific response to specific symptoms. Would-be patients must pass through what Goldberg and Huxley term diagnostic filters (1992). These are successive stages which the patient must travel in order to reach the specialist psychiatric services. Factors affecting the 'successful' detection of problems are complex and include the professional's ability to recognise signs of mental illness as well as the patients 'skill' in showing appropriate symptoms.

The Epistemological Status of Schizophrenia

Despite the tightening of diagnostic criteria and increased reliability the status of schizophrenia remains highly contentious. Reliability in diagnosis does not infer construct validity. Bentall, in Irwin (1995) has articulately pointed out that signs said to be indicative of the *syndrome* of schizophrenia appear lacking in any logical connection between them. What evidence is there that hearing voices and being depressed are together evidence that allows one to deduce the presence of an undemonstrated disease process? Bentall explains that you could reliably diagnose people with Bentall's disease if they had red hair, long nails and more than four Pink Floyd LPs. It would not make it a valid category however and in the same way he suggests that hallucinations, delusions and negative signs are separate problems and do not relate to one another in a meaningful way (Irwin, 1995:15).

Theories of Causation and Their Consequences for Carer-Professional Relationships

Discussion concerning the nature of schizophrenia and its allied disorders stretches inevitably to the consideration of its causes and these have included genetic, biochemical, social and interpersonal factors. The conceptualisation of relatives of people with severe mental illness, as carers, is a recent development. Twigg and Atkin (1994:107) note that relatives were often seen as 'causers' not 'carers' and their role subject to suspicion. There is a growing

recognition that hostile attitudes towards relatives have damaged the relationship between professionals and potential allies. The move towards reconciliation may reflect the desire to utilise carers as resources, as much as it reflects a developing awareness of the burden relatives carry. It is however, against a legacy of mistrust that the relationships between family members and professionals develop.

Mental illness lacks the status of a *real* illness. *Real illnesses* are caused by infections or demonstrable organic processes. Such a sufferer is an innocent victim of their biology and the carer a potential heroine. Some illnesses are not seen as blameless, for example liver disease following alcohol abuse, or lung cancer in someone who has smoked heavily for many years, yet once the illness has been diagnosed and the opportunity to live more prudently has passed, such people can be the subject of sympathetic care. Mentally ill people may never pass fully into the role of authentic patient, but can oscillate between allegations of weakness, moral incapacity, social ineptitude and criminality on the one hand, and declarations of exemption from responsibility (by virtue of illness) on the other. Medics can bestow and take away diagnoses, with them responsibility for the sufferer's plight. Suspicions about personal weakness, and guilt about malingering are also produced internally by the sufferer. Mentally ill people themselves often feel unconvinced about the authenticity of their problem. Low self esteem, itself a symptom of depression, can feed into the process. The ambiguous status of mentally ill people has inevitable consequences for the carer. How can one respect a person who supports someone who is not ill, but fundamentally idle, unkempt, self pitying or aggressive? To support such a person can only perpetuate their behaviour and represents an exercise in self deception by the carer, who is avoiding the reality of the person's defective personality.

The position is further complicated in that mental illness is a broad category, and encompasses a range of problems, some more credited with illness status

than others. Hence some people may be more prepared to recognise schizophrenia as an 'illness' than anxiety or alcohol dependence. Schizophrenia may be perceived in a paradoxical way however, because the user often appears idle or awkward rather than ill and then the illness label will may be challenged. Unfortunately actually using the word may justify the sick role but will also cause stigma and fear.

Is Schizophrenia an Organic Problem or a Social Strategy?

Clare notes that some psychiatrists think that although we cannot reliably demonstrate the underlying organic pathology of schizophrenia at the present time, it will only be a matter of time before this situation is remedied (Clare, 1983). That our position is equivalent to that of medical knowledge concerning syphilis prior to the discovery of the organism responsible. Psychiatrists with a heavily biological disposition see mental events as epiphenomena of physical changes or abnormalities. Eventually science will be able to correct the malfunctions. Mental illnesses will then disappear. Many people hold this view particularly in relation to schizophrenia and bipolar disorder. The view has been held to a lesser extent in relation to 'neurotic' conditions such as phobias and anxiety but there are those who advocate that obsessions are the result of brain abnormality and are not socially determined (see Rapoport, 1990).

The Influence of Freud

Attitudes towards the families of mentally ill people can be traced to the foundations of psychiatry and we owe the attention paid to early life experience to the work of Freud. Freud did little clinical work with very disturbed people experiencing psychosis, but worked with people suffering milder 'neurotic' disorder. Based on his belief in the critical nature of the first five years of life he sought the root of mental problems in early relationships (Clare, 1983). Although psychoanalysis is less influential in the UK it remains a powerful ideology in the USA. Its efficacy and the scientific basis of its assertions

remain bitterly disputed. Nevertheless the suggestion that adult behaviour has its roots in faulty socialisation, especially in early childhood, has been absorbed into mass culture. It is also understandable for parents to feel guilty when their child experiences profound difficulties and to search for reasons for this. The search for reasons reflects our need to make sense of things and to exercise control over our destinies. With schizophrenia and to a limited extent bipolar disorder the quest for cause has become confused with apportioning blame.

Family Theories of the 60s and 70s

The aetiology of mental illness is poorly understood, and in the 1960s and 70s the subject became the target for speculation. Attention paid to pathology in early relationships led to an evaluation of the quality of family dynamics and in particular to the role that the mother might have played in 'causing' psychosis. Hence Freida Fromm-Reichmann's concept of the 'schizophrenogenic mother' (Carstairs and Kennedy, 1978). Carstairs and Kennedy note that this concept has faded from professional popularity as it is recognised that the mother-child relationship is more accurately portrayed by the concept of 'dialogue' where both mother and baby act and respond to one another.

Lidz attempted to conceptualise problems within the family dynamics that might be causative in schizophrenia. Writing in 1963 Lidz held that normal development relied on family members being adequate parental figures. If one parent is dominant, aggressive and demanding and the other weak, withdrawn and inadequate, there would be an abnormal pattern of social relationships which he termed a 'skew'. Where parents are emotionally withdrawn or hostile towards one another Lidz termed the situation a 'schism'. Though rather different he felt that such pathological family dynamics would prevent the child from developing a healthy sense of identity and that this might make him more vulnerable to schizophrenia. At first glance it is apparent that concepts like schism and skew are complex, awkward to operationalise and submit to

verification. In 1963 Sanua (Forrest, 1968), also noted that no control for cultural differences between ethnic groups had been made in trials. Observed differences in attachment patterns could be understood in terms of ethnicity. Forrest (1968) also makes the observation that it has not been demonstrated that schism or skew are more likely to be correlated with schizophrenia than with alcoholism, ulcers or juvenile delinquency , or even normal behaviour.

Despite the nebulous and unverifiable nature of Lidz's concepts they are easily recognisable in Chapman's 'Textbook of Clinical Psychiatry' (Chapman, 1976). Chapman states that the schizophrenic cannot tolerate close interpersonal relationships and withdraws to escape the pain of contact. He attributes the development of schizophrenia to a combination of unhealthy relationships during childhood with parents and others. Socio-economic and cultural pressures may also play a role. His (Chapman typically talks about the person suffering with schizophrenia as male) relationships are experienced as stressful, clouded by anxiety and when pressured he retreats into an inner fantasy world.

In many cases the mother-child relationship is especially traumatic. The mother's basic attitude toward the child is harsh, rejecting and depreciating, but in addition she often has a marked need to dominate him. The mother and child often become locked in a sick relationship in which the mother grapples the child to her with abrasive, loveless dominance, and the child clings to her in frightened, guilt-ridden dependence (Chapman, 1976:273).

It is not clear upon what empirical evidence this is based, yet Chapman writes with authority and the message he conveys is clear. He goes on to describe the typical schizophrenic's father as 'distant and emotionally uninvolved with the child' (Chapman, 1976:274).

Another influential theorist, Bateson, writing in 1956 (Bateson et al, 1956) believed that schizophrenia resulted from a failure to learn to distinguish clear messages in communication with other family members. Parents typically convey one message verbally but confuse the issue by also conveying conflicting signals, possibly by non-verbal means. Bateson paid particular attention to the role of the mother who he characterised as ambivalent towards the child. Unable to tolerate intimacy she would reject his (sic) advances and, unable to accept her guilt at her rejection of him, she would punish him for retreating from her. The child is left confused and unable to form relationships where there is any true intimacy. He also learns that people do not mean what they say. Bateson coined the phrase 'double bind' to apply to such situations. Trapped in the situation through a fear of punishment of the withdrawal of love, the incipient schizophrenic may learn to defend himself/herself with the defences of becoming anxious and suspicious, withdrawn or making light and laughing inappropriately. Bateson's model based on clinical material attempted to understand how characteristic thought disorder might have arisen from learned experience. As in Lidz's work, criticism of the parents, especially the mother, is prominent. Bateson emphasises her twisted emotions and claims that if the child turned to the father for support, he did so in vain as the fathers of schizophrenics were usually weak men (Bateson et al, 1956).

This work raises the question of how one may make reliable generalisations from clinical data where there is no attempt to draw a random sample. Bateson et al (1956) acknowledge this problem, but their theory was the result of a genuine endeavour based on the clinical material that they have examined. Although I worked intensively with the families of 'schizophrenics' I am unfamiliar with their observations. Perhaps a clue to this problem is in the psycho-analytical orientation of the therapists whose work they observed. Such therapists would tend to focus quite naturally on aberrant relationships in

early life and view these as providing the root disorder that might lead to the development of a psychosis in adulthood.

The mothers of men with schizophrenia are repeatedly insulted in the literature. However, if questioned at depth about their feelings for their child many if not most women would acknowledge a degree of ambivalence. Few women or men can love perfectly, and few children are such that they can offer perfection in return. Bateson's model is misogynistic and plays on insecurities and shortcomings of which many parents are all too aware.

R D Laing wrote a number of books about schizophrenia in the 1960s. He complained that the psychiatrist did not seek to understand the language of the 'schizophrenic' but only sought to confirm the presence of psychosis from the observation of signs and symptoms. Laing offered a phenomenological approach to the experience of schizophrenia and describes the sufferer's retreat into an inner world of fantasy. The inner world, however, turns from a sanctuary into a prison as the self cannot survive without contact with others (Laing, 1990). Laing's sensitivity to the experience of schizophrenia in human terms is compelling. At a time when sufferers had no voice of their own in the field of psychiatry, he emphasised the need to see sufferers as people, not a collection of 'utterances' (1990).

However, Laing also emphasised the role of the parents, especially the mother, in the genesis of the disorder. His case studies quote metaphorical comments made by sufferers which he interprets as referring to parents (Laing, 1990). The representativeness of his cases must be questioned as to how far one can generalise from such individual material. Another problem with this work is that though one may empathise with a 'schizophrenic's' feelings about his situation, this does not mean the patient's view is an accurate portrayal of the whole situation. Hence, one may accept that a sufferer feels driven insane by his mother, but that this does not make it literally true.

I began this research by revealing my autobiography which allows the work to be assessed in the context through which it was created. It is unfortunate that Laing's work was interpreted without such material and has been treated as value neutral. In McLynn's review of the recent biography of R D Laing he draws attention to Laing's emphasis on schizophrenia as associated with 'an adverse family background' (McLynn, 1996:17). It would appear that rather than having a neutral attitude Laing may have resented his mother.

Laing also developed the concept that passage through psychosis under the guidance of an enlightened therapist might lead one to a heightened sense of self and inner knowledge. Clare (1983) notes that Siegler and Osmond refer to this as the 'psychedelic' model of mental disorder. The suffering of so many psychotically ill people makes this view naive at best. Despite the limitations of his approach and lack of prescription for effective treatment, Laing's work gained prominence in the media and sold many books. Laings' romanticised view of the value of the psychotic 'trip' can be compared to views expressed about the relationship between TB and creativity. Clare quotes Sontag who examined literature of the 19th Century which claimed that developing TB was a route chosen by artistic, sensitive people who sought to retire from the world. In the light of current knowledge, such an interpretation appears ridiculous (Clare, 1983).

The labelling theorists writing in the early 1960s (of whom Goffman is a prominent example) drew attention to the process by which society 'labels' those who break its rules as 'deviants', and the negative effects the process has upon the person. Regarded as different and unacceptable by the main stream of society the deviant's view of his own self worth is unavoidably distorted by the process. He/she passes through a 'moral career':

persons who have particular stigma tend to have similar learning experiences regarding their plight and similar changes in conception of self - a similar 'moral career' that is both cause and effect of commitment to a similar sequence of personal adjustments (Goffman, 1986a:45).

In his work about psychiatric institutions, 'Asylums', (Goffman, 1986b) describes the process of abandonment when the relative (who is deemed to have insight concerning what is best for the patient) signs them into the hospital. Goffman also suggests that families may label a member as ill and so cleanse themselves of any feelings of guilt or ill health. Such scape-goating is therefore functional for the remainder of the family at the expense of the member who is deemed ill and may then have to face compulsory detention in hospital. Clare (1983) observes that Goffman pays more attention to the act of labelling on the part of society and does not balance this with an appreciation of the mentally ill person's disturbed behaviour and suffering. Goffman's model treats the 'deviant' as a neutral entity which many psychiatric patients clearly are not. (Clare, 1983). Acknowledging the limitations of the labelling approach it has served to raise awareness of the potentially stigmatising effect of diagnosis, and much psychiatric provision. Many people diagnosed as psychotically ill also carry the physical stigmata common amongst those who use anti-psychotic medication. Their strange expressions and movements make them instantly recognisable and deny them the opportunity to be judged as individuals of worth on their own merits.

Another influential theorist, Szasz, questioned the objectivity of psychiatric diagnosis. He contrasted the tangibility of physical pathology with the subjective-based diagnoses that characterise psychiatry and he suggested that whereas physical medicine identifies and treats 'real' illness based on verifiable pathology, psychiatry is a pseudo medical science and it is a guise for the enforced 'treatment' (control) of social deviants. Szasz made an analogy between:

the belief in witchcraft and the persecution of witches with the belief in mental illness and the persecution of mental patients (Szasz, 1971:XX).

Szasz believed the process of treatment in any *real* illness involved the sick person recognising their disorder and voluntarily seeking treatment. These elements were absent from what he called 'institutional psychiatry' which forced those deemed ill, who did not recognise their need for treatment, to become involuntary patients. Szasz saw the concept of mental illness as being sufficiently pliable to be adapted by the psychiatrist to whatever purpose he seeks and in this sense it becomes a powerful tool of social control (Szasz, 1971).

Szasz used emotive language in his influential writing. The comparison with witchcraft, terms such as 'persecution' and the likening of treatment to 'torture' (Szasz, 1971) provide a clear message to any involved in the compulsory hospitalisation of mentally ill people. Additional guilt is poured on relatives who probably already have difficulty in accepting such uncomfortable responsibility. Yet Szasz makes no contribution as to how one is to deal with people who lack insight into their disordered behaviour. He portrays the relationship of patient and doctor to be by definition contractual. Psychotherapy requested and paid for by the client may be the treatment of choice for those with minor psychiatric disorders or emotional difficulties, but those with psychotic illness (and a lack of insight) may eventually be 'treated' through the criminal justice system if they do not receive compulsory psychiatric care. At a recent conference (1996) a carer was incensed by Szasz' insistence that so-called mentally ill people are culpable and should be punished for their behaviour.

The relationship between family disturbance and the aetiology of schizophrenia is complex. Wynne and Singer writing between 1963 and 1965 sought to test the relationship in a more rigorous way. They noted that previous trials had not

been blind and that 'schizophrenics' (sic) and the controls were not adequately matched. They also suggested that family disturbance might be caused by the pressures of raising a disturbed child. Wynne and Singer studied family interaction through taped interviews and psychological tests. They identified three types of thought disorder: 'amorphous'; 'fragmented'; and 'mixed'. Research concerning 35 families showed that by assessing the interaction of the family, a rater could predict the diagnosis of the child. It was also possible to allocate children to the correct family, with a degree of accuracy within statistical significance. It was concluded that genetic and learned factors were in operation.

The pre-schizophrenic child is thus doubly unfortunate as he is born with a nervous system geared to unsatisfactory modes of operation, and he is reared in an environment where the context of references of communication are constantly and vaguely shifted, the areas to which attention is directed are not crisp and clear-cut, but are ill-defined and amorphous and fragmented over such a large series of items that meaning cannot properly be integrated (Forrest, 1978:443).

The work was illuminating, but attempts to replicate it failed. Nor is the mechanism by which dysfunctional communication patterns operate to 'cause' schizophrenia understood (Forrest, 1978).

Within the fields of medicine and psychology understanding of the causes of schizophrenia (since the early 1970s) has focused prominently on the study of what is termed 'high expressed emotion' or high 'EE'. Examination of people living in long stay hospital wards had revealed a lack of social skills associated with institutionalisation, but those discharged to relatives, who had close emotional ties with the patients, also fared poorly and were prone to early relapse (Brown et al, 1972). Rigorous examination of the constituents of relatives' behaviour correlated with poor outcome revealed that a high level of

hostility, critical comments, and emotional over-involvement, were linked to relapse (in the first nine months), regardless of other factors such as the length of illness, age, sex, job record, or type of illness (Brown et al, 1972).

Recognition that high expressed emotion was positively correlated with early relapse led to programmes being established to educate relatives in developing a better understanding of the illness, and in order to effect a reduction in the level of expressed emotion. There have been numerous studies, but one such programme demonstrated a clear benefit when psychotic medication was provided in connection with an educational programme for relatives (Leff et al, 1985). However, the numbers were small and complicated by the suicide of two of the experimental group patients. The work on high EE and the training of relatives has become an established and accepted practice. Kavanagh (1992:601) notes that the link between high expressed emotion and early relapse in schizophrenia is now widely accepted and that it is increasingly recognised that the concept can be used to predict outcome in other psychiatric diagnoses, such as depression. The model is also being used to help families of bipolar people, where family breakdown following disturbed behaviour is a frequent consequence. Huckle (1993) suggests that as with schizophrenia sufferers, the families of bipolar people may often experience severe, long term difficulties and deserve help in understanding their relative's illness. Such help he argues can be provided through education projects similar to those now used for families of people with schizophrenia.

There has understandably been a feeling expressed by the carers' organisations that although the high EE material has not blamed relatives for causing the mental illness, it has implicated them in relapse. It can be offensive when one's desperate attempts to help a disturbed relative are seen as causal (Kavanagh, 1992:610). Kavanagh suggests a more complex and interactive approach, given that,

patients' symptoms and other problem behaviour elicit frustration, distress and concern from other people, and prompt attempts to cope. Unfortunately, these attempts at coping sometimes involve critical or intrusive interactions. The resultant negative emotions exacerbate patients' symptoms and make it more difficult for them to function effectively (Kavanagh, 1992:611).

This latter view acknowledges the biological vulnerability to stress and to developing florid symptoms in response to minimum arousal. It recognises that relatives' 'emotional' reactions may be no more than understandable reactions to distressing behaviour, but it sees the carer as an appendage. Any drive to educate relatives and assist them in developing coping skills is derived from concern to reduce relapse rates and does not reflect a conscious motivation to empower, protect and support carers. I must also comment that though the high EE work has been influential for some years, in the geographical area in which I work and study such intervention is not routinely available. Newcomers will face confusion and emotional upheaval without the benefit of such support. The presence of so-called psychoeducational programmes, based on the high EE approach, may be associated more with the presence of professionals involved in research than with the needs of families.

Current Theories on the Causation of Schizophrenia and Allied Problems

The family causation theories have largely faded from academic popularity. There have been benefits, however, the questioning of diagnosis as a scientific event, and its re-formulation as a social process has encouraged scepticism, and a challenging of the dominance of the medical model.

Contemporary theories increasingly recognise mental illness as having biological, psychological and social aspects. Even disorders with a 'clear' organic pathology reflect social inequalities. They vary between the sexes, races, and as a reflection of poverty. A genetic component to schizophrenia is now commonly accepted and twin studies show a concordance for monozygotic twins of around 50% (but this still leaves another 50% who do not develop schizophrenia) (Stromgren, 1982). It is important to ascertain what processes have prevented someone with an identical genetic make-up acquiring mental disorder. Bipolar disorder shows an increased risk to first degree relatives and a high concordance between monozygotic twins (Milligan and Clare, 1994), but again sharing one's genes with a sufferer does not predict the presence of the illness. Other factors, whether social or psychological, are clearly at work. Causation in social life is complex and events are better conceptualised as the consequence of a complicated interaction of variables.

The genetic predisposition model offers a limited contribution to the understanding of the aetiology of severe mental illness. Through what mechanism(s) do the critical differences operate to produce the familiar clinical pictures? Attention has focused on abnormalities in the activity of neurotransmitters, in particular dopamine in schizophrenia and serotonin, dopamine or noradrenalin in depression. Chemical treatments affect the availability of these neurotransmitters. It remains that abnormalities in these chemicals may often be secondary to other changes, biological or psychological, and may not be the 'cause' of the mental symptoms, but a



consequence of them. Brown and Harris (1984) note that the somatic signs of so called endogenous depression may be secondary to changes in thought.

Recent work has availed itself of modern brain imaging techniques and these have made it possible to examine the workings of the brain in a way not previously possible. Torrey et al have studied twins and where monozygotic twins proved discordant for schizophrenia they observed brain abnormalities in the sick twin.

In fact, some evidence of structural change in the brain was found in almost every twin who had schizophrenia, but these abnormalities were non-specific and on a continuum of severity. This picture together with the variety of deficits found by neurological examination suggests that schizophrenia involves scattered damage to varying parts of the brain (Freeman, 1994:30).

Torrey et al go on to suggest that these findings place schizophrenia alongside Alzheimer's disease or Parkinson's disease as disorders of the brain. It follows, therefore, that family theories have become redundant though social factors clearly influence course of the illness (Freeman, 1994:30).

It would seem that the family theories of causation have left an unfortunate legacy for carers, and although there is a definite move away from implicating families in causing the disorder, they may now be held culpable for relapse through the EE model. Sedgewick (1982) argued that the anti-psychiatry movement drew powerful allies away from the mental health lobby and created the fashionable impression that schizophrenia did not really exist. Post-revolution, such anomalies would disappear, and those wrongly labelled would be able to adopt their rightful places in the mainstream of society. Such theories made liberals suspicious and condemnatory towards relatives who permitted the labelling of their unfortunate family members.

There is a surge of enthusiasm concerning the role of carers in almost every field of community care, but the position of carers of the mentally ill remains tenuous. Staff trained during the ascendancy of anti-psychiatry, or where family were considered peripheral to professional care may be slow to reappraise their attitudes. Some modern literature continues to perpetuate the allegation that families cause mental health problems and use diagnosis as a means of avoiding their guilt. Breggin argues that it is family organisations who are the driving force behind funding research into the biological basis of mental illness and that they do this to avoid facing the reality of their own guilt (Breggin, 1993).

Breggin does not go as far as to directly accuse families of driving their children mad, but says 'in my experience not all families with children in spiritual despair are abusive, but there is almost always a severe psychospiritual incompatibility between the labelled patient and one or both parents' (Breggin, 1993:43). He adds that evidence supporting the belief that high expressed emotion is linked to relapse, and that teaching adaptive methods of communication improves the prognosis in his opinion 'strongly substantiates a familial origin for so-called schizophrenia' (Breggin, 1993:42). Breggin does not advocate guilt but suggests that it is never too late to see the light and that 'parents who freely acknowledge the harm they have done can experience enormous moral relief' (Breggin, 1993:49). One wonders which parents have not searched through every memorable, and less than memorable, event in their child's life to seek causes for their illness. Literature in this vein fuels the self doubting that most relatives suffer and gives it academic credibility.

This situation feels particularly distasteful. There are clearly carers whose behaviour puts pressure on family members to the extent that they may present psychiatric symptoms. Unsupportive oppressive marriages, the sexual abuse or cruel criticism of children, and the inability of some individuals to express

affection may trigger mental health problems. Whatever the behaviour, whether conscious, culpable or otherwise, I would suggest that the role of the professional is to ascertain the strengths and needs of the user and of their supporters. Help should be offered and should recognise their abilities and capacity to cope realistically, compassionately and without passing judgement. It remains to be said that if *social* forces are held to be paramount why has attention focused so heavily on the role of families as perpetrators and the role of larger social institutions been largely ignored? The 'expressed emotion' of family members may only be a reflection of their struggles to cope with the uncopable within a societal framework that offers negligible support.

Carers, family, whatever they are known as, have been denied the opportunity to define their own experience. Increasingly users *are* locating the nature of their 'symptoms' outside of the pathological explanations offered by professionals. This discourse is now recognised through the Hearing Voices networks (see Romme and Escher, 1993). The following section of the thesis allows carers to relate their experiences and encounters with the system, not as appendages to the patients, or as culprits, but as human beings who have suffered particularly challenging experiences.

Chapter four

Introducing the Carer's Story

The following chapters trace the experiences of carers in the current study. (Material concerning my own caring is presented in bold print to enable it to be easily recognisable). The data is offered in terms of 'the carer's story', in recognition that carers encounter particular challenges especially during the early phases characterised by the identification of the mental health problem, the search for help, and their initiation into the psychiatric system. At a certain point the experience of caring can begin to repeat itself with cycles of illness, caring, admission, and recovery. It is not easy to portray these experiences through the linear framework of a thesis, but I have drawn attention to these aspects of caring for severely mentally ill people as they unfold.

The thesis attempts to present the *carer's* view of their role, the impact that their relative's behaviour has on family relationships, and the response they encountered from the system. As I have previously argued, the professionals, and latterly users, have been actively engaged in defining how mental illhealth should be understood and responded to. There has been an inherent assumption that family supporters have no legitimate right to be involved in this debate. The data supports the argument that carers' lives are fundamentally affected by the mental illhealth of their relatives at a time when they can no longer represent their needs themselves because of the impact of mental illness.

The thesis includes reference to the literature concerning *carers* as this is how family supporters are now legally recognised. This literature, however, tends to reflect the area of mental health inadequately. Professionals and the public appear unconvinced by the transformation of culpable 'schizophrenogenic' families into benign carers. Literature specifically on carers of mentally ill

people is sparse. Two striking examples are the Greer and Wing study published by the National Schizophrenia Fellowship in 1974 and the Clausen and Yarrow papers published in 1955. Though frequently cited one is forced to ask why they have made so little impact on actual practice.

Perring et al (1990) have drawn our attention to the need to try and understand how carers of adults with mental health problems see their situation. Attention to carers has tended to reflect professional concern over their usefulness and rarely any true desire to recognise their own needs.

Who are these Carers?

It appears to be a recent development that some people supporting those experiencing mental illness have regarded themselves as "*carers*". I can remember when I first began describing myself as a carer to others who had adult children experiencing schizophrenia - it felt awkward, did I have the right to refer to myself as a member of this category? How do people make such a transition, if at all? We need to ask such questions, since community care legislation designated carers are afforded particular rights. Although caring has always taken place in that humans care for their young, sick, and at times the vulnerable, the way that care is provided, by whom, where, and for which categories of need is mediated by social convention. The users and carers spoken of so frequently in the world of social and health care are creations of particular structural forces and are social constructions. In the current study interviews involved the carer looking at their emerging career in retrospect. Carers often found it very difficult to remember the exact details. I have been able to refer to my notes and have traced changing perceptions and roles through the course of the study. Where the research diary is quoted it is practically verbatim, and I attempt to capture the flavour of the entries which can be distressing, angry and confused.

Carer is a difficult term. Most of my clients have long, frequent periods of ill health and their families are thrown into a formal

caring role. Like it or not I feel such users are virtually forced to accept dependence but there are probably other groups whose illnesses are more concealable where those living with them can not be called "carers". The use of the term has extended an institutional model of care into the community. It is thought professionals need to perceive someone as being responsible for these people. My partner prefers me to be known as wife, partner, etc. rather than carer. (personal caring diary, May 1992)

After all, everyone (well, almost everyone) provides some support to their family and, in particular cases, to people outside of their family. This must mean we are all "carers". The caring role, seemed at the time of the diary entry, to emphasise a degrading, child-like dependence. Writers experiencing disability, especially physical disability, have emphasised the disabling features of society and how it disadvantages individuals who differ from the majority (Twigg and Atkin, 1994). These sentiments are expressed pertinently by Mike Oliver who advocates that "it is time that the real enemy was confronted and that is the disabling society which fails to provide the necessary understanding, resources, and enabling services to ensure that different is positively welcomed and celebrated rather than constantly denigrated and denied." (Oliver, 1995: 12)

Oliver's letter (above), to the social work press was also vehemently resentful about the portrayal of the disabled as "burdens" and he linked this to the demands of so called carers for respite provision. "Respite" places would be built to accommodate disabled people, because of the burden they cause to "carers". Oliver believes "that the claims made about the wretched lives that carers lead are often over-stated to make a political point and certainly go far beyond the reality suggested by independent research." (Oliver, 1995: 12) It will be important to separate the themes of burden and culpability, and to recognise that they can co-exist. Carers may experience strain without asserting that their relative's disability is ruining their lives. To claim to know

the extent of another's burden is to tread dangerous ground and Oliver's assertions go too far.

Caring frequently takes place in the carer's own home, it always "takes place in a relationship" (Twigg and Atkin, 1994: 9). Relationships with professionals arise as a consequence of the caring need. Persons will know their GP but it is unlikely that the social worker or community nurse will have been known to the family prior to the illness or care need. Carers, on the other hand, often know the person they come to support very well. The relationship may have been loving, acrimonious or neutral. It cannot be separated from the care that is provided.

Caring and Reciprocity in Family Relationships

Jordan notes that the values placed on the caring services people perform are in contrast to the world of work and contractual obligation (Jordan, 1990). Informal care takes place within a framework of mutual responsibility and reciprocity.

If we are to find ways of valuing carers, then it is important that we recognise the morality of caregiving and the values by which carers live. It seems to be a morality in which interdependence and mutual help form part of long term patterns of relationships within a system of kinship (or occasionally of friendship). In this system, all members are to be included and assisted and valued for who they are rather than what they can do. When problems and conflicts arise, members try to resolve them by negotiation in such a way that friendly relations are maintained and emotional bonds remain intact (Jordan, 1990: 20)

Using this model, caring may be seen as a continuum. Nearly everyone is involved in providing practical, financial, physical, and emotional care to others in their family or close circle. These activities are usually reciprocal but the degree of reciprocity is mediated by age and especially by gender. Jordan

notes how women often become the carer, and that there are strong norms encouraging this (1990: 22). Although caring cannot always be reciprocal at the time, there is an expectation that when an illness is resolved the sick person will return to offering support to others. At one end of the continuum, this expectation fades and a member may feel, and to all purposes be, responsible for the welfare of another adult. The hope of full recovery and future reciprocity becomes remote. Yet even severely disabled people can offer reciprocal care to other family members, and though this may be limited, its existence should not go unrecognised. Hence, it may fall on the cared for person to offer emotional support to the despondent 'carer' or provide practical help when the carer themselves falls sick. What is important is that the nature, amount, and reliability of such reciprocal care is frequently uncertain and unreliable when the potential supporter has severe mental illness.

What Sort of Things Do Carers Do?

The main body of the literature concerning informal care pertains to people who need practical help, especially with personal hygiene and mobility. Photographs in the media or in literature available at social services departments often depict an older person in a chair, or an adult in a wheelchair, with the carer standing dutifully behind (this is usually a woman in her forties or fifties). Few supporters of adults with severe mental illness would identify with these images and they are unlikely to feel that services designed to meet the needs of such groups would be appropriate for them. This may present a barrier to mental health carers viewing themselves as carers at all.

There is a large amount of literature concerning the informal care of older people who may be physically frail or suffer dementia. Lists of common tasks/areas of care/needs are used in survey research of caregivers of older people. These include cleaning, cooking, shopping, controlling finances, attending to incontinence, washing, feeding, and getting up at night. This list extends, however, to issues that will be much more familiar to people supporting adults with severe mental illness. These include users' doing things

that embarrass the carer' and suspiciousness, 'seeing or hearing things that are not there' and being restless. (Zarit and Zarit, 1982: 466) The difficulties that are associated with physical conditions frequently extend to encompass emotional and mental health needs. Caregivers of relatives suffering illnesses such as cancer (Clipp and George, 1992: 1074) may be concerned with coping with depression in their relative as well as physical incapacity and pain. It appears that disabilities are more commonly associated with emotional and behavioural needs than the popular conception suggests. Given that this is the case, why has there been such difficulty in conceiving of carers of the mentally ill as carers? Twigg and Atkin (1994: 105) note that:

The traditional conceptualisation of caring has been strongly task-focused with activities like lifting, toileting and dressing, seen as the defining feature of caregiving. These physical tasks, however, are rarely of central importance in relation to mental health problems and are commonly absent. As a result, caring for someone with mental health problems is often not regarded as 'caring' at all.

Having a real, ie. physical illness, may legitimise emotional distress. This legitimised disability is absent in much mental illness. Mentally ill people may be felt to be 'upset about nothing'. Twigg and Atkin (1990: 105) suggest that caring cannot be defined by one activity alone but is comprised of a number of components. In the case of mental health this includes assuming a sense of responsibility for someone where this would not normally be appropriate. For example, one may not have expected to need to watch over an adult child or spouse in order to prevent them from harming themselves, or inadvertently setting fire to the house. This type of caring is most blatant in the psychiatric hospital where patients are clearly watched over and may not be allowed to use the toilet alone. In the community people with mental illness may also need supervision and, practised skilfully, this may be invisible to both the cared for person and to outsiders. This only endorses the suggestion that the carer does not do anything important.

There is an added dimension that the mentally ill person may look well and may even be defined as such by agencies such as the DSS. Much mental illness is also episodic, usually lacking physical signs. To the outside world, the mentally ill person may appear healthy and just idle.

The situation is compounded in that the generic expression of mental illness can be used to refer to emotional distress or to a severe, debilitating disorder. Users of services may come to have internalised their marginal status and can be unsure themselves whether they are really ill at all. Ratification of a user's position by professionals may be inconclusive, and this makes the status of the carer particularly tenuous.

Despite regular medical attention and a clear diagnosis my partner would often return to this theme. The discussion might however be instigated by sarcastic comments made by friends, relatives or even a doctor.

"Sometimes I think I must really just be lazy and that there is nothing wrong with me. All I need is an enormous kick up the backside."

The ability of psychiatrists and other professionals to confer the sick role on this group is impaired and there persists a common sense view that a large, able-bodied young adult can be cured by a "dose of hard work". The marginal status of the patient extends to the carer. If the patient is not ill, just lazy, they do not need a carer. The appropriate duty of a relative is to deliver a blow to their rear end, (or at least to remove the support that encourages their idleness). Women in particular may suffer the unspoken accusation that they have cultivated inappropriate dependence in an adult child and hence secured a permanent parental role for themselves. The frequency with which one observes mothers supporting sons suffering from schizophrenia may have more to do with the permanency of the mother-child relationship than with over-protectiveness.

There have only been a small number of studies concerning family carers of mentally ill adults but these span back forty years drawing professional attention to the activities that family carers perform. Mills' study of 'patients' in East London was published in 1962 when the programme of hospital closures was only being conceived.

As a whole mental patients were not simply a liability to their relatives but nearly all of them in one way or other caused anxiety. Apart from fits of violence or attempts on their own life some strained to the limit the patience of their households by their everyday behaviour. (Mills, 1962: 83)

Professionals may be slow to understand the worry that carers feel and may react by suggesting that it is excessive, neurotic, or that the carer should put the situation out of their mind and let the mentally ill person manage their own life.

I had left my partner slumped over his breakfast unable to stay awake. Though I had cleaned up and got our son ready for school I felt my partner wasn't well enough to be responsible for him, as I wouldn't be back until nine at night. I telephoned the psychiatric nurse and left a message. My partner had a selection of symptoms suggesting Lithium toxicity: clumsiness, lethargy, slurred speech and diarrhoea and he needed medical supervision. The message didn't reach the nurse and no visit was made. I escorted my sleepy partner to the surgery for his blood test the next day determined to express my concerns. Feeling emotional and powerless it was suggested to me that I would feel better if I was at work. (personal caring diary, July 1995)

The lack of understanding shown by professionals to relatives of mentally ill people was noted in a study carried out for the National Schizophrenia Fellowship in 1974. They drew attention to the absence of recognition that carers received, 'our first main concern is that insufficient recognition is given to the fact that relatives are the real primary care agents'. Greer and Wing 1980: 4) They added that the conceptual status of mental illness was vague and that people had little understanding of how to regard someone falling into this category.

Schizophrenia lies somewhere between those conditions like blindness which though severely handicapping do not interfere with an individual's ability to make judgements about his own future and those like severe mental retardation in which it is clear that the individual will never be able to make such independent judgements. (Greer and Wing, 1980: 4-5)

At the time this study began, in 1991, I was concerned by the comments made by Mills (1962) and Greer and Wing (1980) because I felt little had changed. Evidence from this study suggests that despite the rhetoric of needs led provision and care in the community, it continues to be necessary to draw public and political attention towards the needs of family carers.

Recognising Oneself As A Carer

In recent months (during 1996 when the Carers' Act was implemented) there has been considerable publicity given to the recognition of carers' needs by professionals, and to drawing the attention of carers without services, to their status and entitlement to help. In my home village, which is in a rural area and distant from psychiatric in-patient facilities, (25 miles) a generic group for carers has been started. It is advertised in the surgery, chemist and in shops. The message is clear. "Do you look after someone who is a relative or friend at home, then you are a CARER". Would such a message be meaningful to someone supporting a person with severe mental illness? Do people feel able

to describe themselves as carers and does this label draw people needing support towards accessing it?

The term is now employed in a wide range of situations. A requirement to involve users and carers in service planning and evaluation encourages its liberal employment. I have noted it used by health service managers to apply to any relative of a person in hospital regardless of their degree of involvement, and quality of relationship with the patient. In this sense, the term carer is interchangeable with relative, friend (or even visitor). From a common-sense point of view, carers should actually do something (and this relates to the images of people who push wheelchairs and attend to the personal care needs of frail older people). During the interviews conducted for the current study any formal discussion of 'carers' was negligible. The interviews carried out with subjects referred by the Mental Health Matters' carers' counsellor were somewhat distinct. In order to be referred, either by a nurse, social worker or by one's self the individual had to recognise that they supported someone with a severe mental illness. During the counselling that was offered, the carers' worker could be described as raising their awareness. She certainly discussed people's rights as a *carer* and their implications.

Other people had gradually come to view themselves as carers. This could be because of something said by a professional such as a community psychiatric nurse or social worker. A woman (whose relative was a cousin suffering schizophrenia) praised a consultant psychiatrist who had spoken at a meeting of the Northern Schizophrenia Fellowship. He had emphasised the role of relatives as carers and had drawn attention to their right to be involved in planning care. Mrs T remembered this clearly, although it was over 10 years ago. Even if one comes to recognise one's own role as carer this position requires external validation. This might come through a formal invitation to a meeting prior to hospital discharge or when professionals are prepared to discuss the problem with the carer, without becoming defensive. Mrs C considered herself to be a carer and had sought support from the carers' counsellor, but she lacked external recognition of her status. Other more

distant members of her family, the GP and social worker did not consider her husband to be mentally ill. They defined the wife's expressions of concern over what she believed to be delusory ideas of jealousy as a reflection of a relationship problem. It seems that carers must have the supported person's needs validated by a professional. Without such legitimisation she was in her words, "not a carer, just a liar."

Caring and Relationships

Twigg and Atkin (1994) noted that caring occurs in a relationship. Data from the current study suggests that the relationship (e.g. parent-child, partner, sibling or friend) can have a strong bearing on the way caring is experienced. For example, a mother will expect to care for a child but she will expect the level of personal, social and financial care to diminish when the child reaches maturity. In some societies it is expected that adults will care for ageing parents in their own home. In the dominant white British Society the norms surrounding caring for older relatives may be more vague and permit some degree of choice, though this might also be associated with guilt. Ethnic communities may possess norms concerning caring for dependent relatives but may lack the extended networks that would have supported such arrangements. For many, there was no clear start to their role in caring. This can make questions included in social services assessment forms superfluous at best. For example, one form asks carers for the date "when they began caring'. For the majority, caring involved an intensification of activities that they had always performed, rather than a conscious decision to 'become a carer', in the way one takes up a career as a paid carer.

Mrs E had always stayed at home and looked after her son. (A more detailed list of the subjects and their circumstances can be found in the appendix). He and his father had worked almost seven days a week doing hard physical work. They had needed someone to wash, cook and cope with the household tasks. Caring for her son (40's) with schizophrenia did not present a radical shift in family responsibilities. She was still caring for him but he could no longer work.

When health and social services workers questioned his ability to look after himself, they were challenging the habits of a life-time.

Mrs A supports *all* her children should they need her help. She made no distinction between caring for a relative with gynaecological problems, and looking after her daughter (30's) who has schizophrenia. She regarded caring as a definitive part of being a mother. At times, her daughter would be acutely ill and need extra support. Indeed it was I, and other workers, who viewed her daughter's mental health needs as distinct from physical illness. Mrs A drew no such boundaries.

Mrs B is in her seventies, and had cared for her sister "on and off over 40 years". Her sister had had periods of severe mental illness from the time she had her children, in her twenties. Mrs B lived next door and was on hand to help cook and watch over the family. There were substantial periods of remission in between and Mrs B did not offer this support all the time. As her sister became older, however, her manic depression became chronic leading to her suicide.

Mrs L is a woman in her forties who also cares for a sister diagnosed as having bipolar disorder. She has had periods of illness since she was in her teens. Now in her late forties she can need extra help for months at a time but will then remain well for several years. Mrs L has a nursing background but had no prior experience of mental health problems. When she is needed she is always available especially to look after the children.

Mr and Mrs D are a retired couple who look after their daughter who is in her late thirties and has schizophrenia. Their daughter has assumed a child-like role in the family structure. They *do* view themselves as carers. Their daughter lives with them and, though she has improved, has needed daily care for the seven years since she became ill and stopped working. Mr and Mrs D accept their role. Mrs D says she has acted as a carer throughout her life and

nursed her own mother who was diabetic (and had had her feet amputated) and her father-in-law, who also had a severe mental illness.

Supporters of people with learning disabilities assume their task in an unambiguous way, unlike carers of mentally ill people. (I was able to interview someone in this role). She became a carer when her son was *born* and his disability *diagnosed*. The parent of someone with a learning disability is a carer by nature of the parental relationship, and this pattern flows into adulthood. The parent will usually have had experience in fighting for the child's rights to care and treatment, and will have been encouraged to see themselves as the carer, and to take an active role in care planning. The professional culture in this area has established practice that involves family in the care planning throughout the person's life. From this point of view, the professionals in this field are experienced in acknowledging carers' needs. Relatives in the caring role possess a distinct advantage over those caring for the mentally ill as they enter a system which has created opportunities for their active participation.

The situation of children who care as adults for mentally ill parents is also different. Although closely related, the children may not be the principal carers, as this role is frequently carried out by the person's partner. Mrs EE said, "I thought I knew about schizophrenia. My mum had it and one of my earlier memories was of sitting on her until the ambulance came. But our dad had protected us from it and I didn't find this out until my son became ill." Other young people find themselves giving age inappropriate emotional support and care to a lone parent.

The degree of care people provide differs considerably. Mrs K's mother has schizophrenia but lives independently. Mrs K works full-time and says she copes by rationing the amount of contact she has with her mother. Although caring impinges on her time she is able to pursue her own life and has tried to ensure this remained possible. Depending on the nature of the relationship and the degree of the illness, some people's lives are affected more than

others. Cultural and personal norms will influence the degree to which particular individuals in the family participate in caring.

Jordan notes that it is often women who become carers and that traditions of family duty have encouraged this.

Certain family members, most of whom are women, are lined up for the role of carer by the 'rules' of family relationships. Once they take this role (often feeling that they have no choice about it), then they have no option but to continue as full-time carers until either their health breaks down or the person cared for dies. (Jordan, 1990: 27)

Although caring for an adult child can seem 'natural', there are occasions when it feels inappropriate. Though Mrs N was only too glad to care for her 22 year old son, she was aware that she had expected him to leave home, have a career and probably a relationship. Supporters are conscious that the caring may not be finite and any contemporary responsibilities are framed by that context. As caring parents age they often say that they 'wonder where it will all end'.

Spouse Carers

Four spouse carers were interviewed: one carer supported his wife and had to look after their children, a woman carer had supported her husband and considered herself a carer even after he left their marriage. The two other spouse carers supported older people with dementia, one carer was a man and the other a woman.

The two carers with spouses who had severe mental illness (not dementia), appeared to have a markedly uncomfortable role. Parker observes that spouse carers experience more stress than others who care.

Evidence from studies about head injury, aphasia, and Huntingdon's Chorea shows that it is the loss of a relationship between "equals" that makes caring for a spouse so problematic. Changes in personality associated with these conditions cause the greatest strain as the previously equal partner becomes a "pseudo child", Korner and Fitzsimmons, 1985. If the carer can effect his or her own transformation into a "pseudo parent" then it becomes easier to cope, if this transformation is not possible - and for spouses it usually is not, stress results. (Parker, 1994: 122)

People experiencing schizophrenia are less frequently cared for by spouses. Some do marry but the relationship ends, others become ill when in their late teens and lack the skills or opportunity to find a partner. A study of 62 families receiving the support of a family support worker, trained to provide practical and emotional help for families of people with severe mental illness, found that while 44 per cent lived with parents, 18 per cent lived in a hostel or hospital and 23 per cent lived alone, just 8 per cent lived with a partner (Huxley, 1995: 9). Given that spouse carers are relatively uncommon the number in the sample is not unrepresentative. Two women in the study who had had schizophrenia for most of their adult lives had been left by their husbands although we cannot assume that the illness was the central reason for the separation. For some spouse carers separation had proved emotionally unsatisfactory and one daughter said that though her parents lived apart, they were together almost every day. Mrs K said her father remarried, but 'always felt immensely guilty' at leaving his first wife who had schizophrenia.

Although it is difficult to generalise from the data concerning a small number of cases, the emotional turmoil of Mrs CC and Mr B was powerful. Mr B spoke of giving 24-hour care to his suicidal wife, attending to the household chores and looking after two children. He had also been unprepared for the very intimate care his wife would need. Mrs CC was deeply hurt by the undiagnosed illness of her husband and had struggled to get him medical help. She would have gladly cared for him but, probably due to his lack of treatment, he had left her.

The data on my own situation can enhance our understanding of spouse carers. Caring for a dependent-equal presents an enormous challenge. I found that avoiding the responsibility was impossible as the illness was interwoven into our living space and relationship, and to accept the responsibility was met with resentment by some professionals who suggested that I was over involved in another adult's life. It felt like the classic "double bind" where it was almost impossible to perform the role correctly.

Carer is a very broad term. Although some professionals now use it loosely as a label to cover any relative with an interest in the patient's situation, it is less common for families to use it of themselves. Carers are becoming more conscious of the term through contact with others in 'carers' groups, through literature and through their discussions with professionals. Many people never regard themselves as a carer. This may occur because the difficulty goes unrecognised by professionals or if the carer is unaware that the extra help they offer is something over and above the care that family members provide for one another. Carers whose difficulties are unrecognised, and who exist outside of the mental health system, may be those most in need of help. They will not receive this help without professional validation of their role.

Disquiet

Regarding oneself as a carer, or carrying out caring tasks, over and above those one might usually expect to provide to a loved one, constitutes a response to particular events. Caring is a reaction to a perceived need. In this area of support the carer must first become aware that their relative needs help, and must feel that offering help is an appropriate response. In mental illness the signs of distress can often be ambiguous. Potential carers may react with irritation, confusion, or anger. They may urge the sufferer to 'pull themselves together'.

My partner had felt very low before but had never asked me not to leave him. He said he felt suicidal and begged me not to go to work and leave him on his own. I explained I was 'on call' and had appointments, I had to go out. He said I always put my clients first, and would not help him when he needed me most. It felt like an emotional threat and the 'thin end of the wedge'. If I gave in, what more might be demanded of me, would this become a regular thing? I told him he would have to sort himself out and went off to work. (personal caring diary, September 1993)

Parents may make errors of attribution with sick children who may be listless or irritable before all their symptoms appear; after the family doctor makes a diagnosis, the parent offers an appropriate response. People with a severe mental illness are unlikely to tell family or the doctor that they are suffering from a psychosis. Even if they do visit the GP, there are no diagnostic tests and the doctor may not recognise the problem as mental disorder. The illness may start suddenly or quite insidiously but it is often possible to look back and trace the onset to an earlier time. Behaviour considered to be within the realms of normality at the time, is later viewed with the wisdom of hindsight, and interpreted as pathological. Also the diagnosis will lead to 'normal' behaviour being seen as pathological. Parents often look back to their relative's childhood for signs that something was 'wrong'. Anne Devenson's son, who developed schizophrenia in his late teens, was diagnosed as having had a cerebral haemorrhage at birth. She recalls his early behaviour, emphasising the signs that things were abnormal from an early age. She notes that 'He cries during the day, he cries during the night. The only time he isn't crying is when he is feeding'. (Devenson, 1992:7).

Mrs Q felt that her son had always been a bit "soft", so when he came home and said people were talking about him, she did not take much notice. Given his present diagnosis of schizophrenia, she felt they should probably have taken him more seriously. "I suppose we should have taken more notice of that

but we just thought that he was just soft natured. I said to my husband, the army will either make it or break it for him, and it broke him.”

Others talked about teenage awkwardness. Parents expect young people to pass through difficult phases, and it is impossible to try to decide whether a teenager’s behaviour is abnormal when you lack sufficient experience of teenagers in other families. Schizophrenia frequently develops in early adult life, at a time when family cannot really feel that they know the true adult personality. Mr and Mrs V felt that they could recognise the signs *now*, but could not at the time. “She began to isolate herself, she began to shut herself away in her bedroom. I think she’s always had a job to socialise, I don’t think she’s ever made friends easily. She used to come in from school, go straight upstairs and shut herself in her bedroom, but we didn’t think this was unusual, we thought it was what teenagers did.”

Another couple talked about their son getting on his “high horse”! It was impossible to distinguish this from sheer obnoxiousness. Families enter a period of trying to classify their relative’s behaviour and rarely choose mental illness as a first option. In my case, my partner’s illness stretched back much further than the acute period when we had to seek medical help. There were other incidents that began to fall into place only when his illness became so exaggerated that it could no longer be seen in terms of ‘being on a high horse’ or plain bad temper. Most of the sample were looking back at incidents that had happened ten, even forty years ago, and they found it difficult to remember. Even Mrs N, whose son had been ill for only two years when I talked to her, found it difficult to remember clearly. There may be one crisis after another and it becomes impossible to recall incidents clearly.

Carers will often lack the corroboration of their sick relative, who may place a different interpretation on events, or simply have no memory of the period at all. By looking through my research diary, I was able to trace oblique references to my partner’s early illness. They were included in the diary in a cryptic form with all the details excluded. There is a change in style from rather formal analytical

entries concerning patients and their families, to my own feelings. I began to believe that the 'personal was political' and that this material should not be ignored.

As soon as the difficult periods are over I seek to reassemble my confident veneer and distance myself from the problem. I have no idea how representative my experience is but can only guess that it is relevant. I believe that a carer's distress is probably compounded as mental illness bears a genetic component and it is likely that people are coping with more than one difficult person in their family, or that they themselves are less able to manage than a more emotionally robust individual might be. It is a double edged weapon, I am at once sensitised to emotional distress and able to empathise, but I also lack the necessary emotional and physical stamina. It is never clear where, or how an 'episode' began. Simply to say that difficult social circumstances, misfortune at work and family rows gradually gave way to depression and suicidal thoughts. There is no dividing line. The illness, so called, and one's social circumstances and personality are intertwined. I ask myself why we can't have a normal home, yet I realise others are probably hiding their own troubles. It has been so hard to summon the energy to wish to see each day out lately. Now it appears over I quickly forget and will be acutely embarrassed by what I have written but some moments have felt like hell. (personal caring diary, November 1992)

I cannot accurately recall this time but, on the day before I made this entry, my partner had started to shout at me. I could not understand why, or what I had done. He punched the door, cracking it. My language is interesting. There is a flavour of denial. Incidents are not described fully and terms like suicidal are not attached to the individual who felt them. Though I could not understand why he had become so angry, I believed I must be at least partly to 'blame'.

We are taught that reasonable people should acknowledge that it takes two to cause an argument, and that relationship problems are aggravated by the actions of both parties. I will return to this theme at a later point. One can recognise that I understood my position from a systemic standpoint. I looked at our family difficulties, and regarded them as indicative not of a problem occurring in any one individual, but as symptomatic of a dysfunction in the family symptom. As many women in conflict with a partner do I searched my behaviour for things that might have provoked him. I could recognise his 'depression' but could not relate that to other problems that felt like personality or relationship difficulties. This entry, like so many, was cryptic to avoid having to acknowledge the emotional threat of the problems. As soon as the crisis was over every attempt was made to forget what had happened, and no recognition permitted of my vulnerability. I believe this served as a valuable coping mechanism, but the amnesia was inevitably punctuated by uneasiness when the difficulties returned to confront me.

Some carers were not closely involved with their relative when the problems developed, but became active when the relative had been in hospital, and needed support. This pattern was more typical where the relationship was more distant, for example between siblings rather than between parents and children or partners. Mrs T gleaned the details of her cousin's illness from her uncle. Her cousin became unwell when studying, and her uncle had needed to make numerous visits to the town where he was staying, but Mrs T and her husband had been living abroad at the time and knew relatively little about this.

Mrs L and Mrs B both cared for their sisters. Though not intimately aware of the difficulties that were developing, they lived close enough to be conscious that there were problems. It was probably the women's partners and children who felt the impact of the illness first. It was not realistic for me to contact the partners who had left the users some years ago. Relatives more distant from the sufferer may possess a distinct advantage over those who are very close and live in the same house. Work by Weissman and Paykel (1974) demonstrated that in the case of depression, women's relationships with

partners, children and those with whom they had been very close deteriorated most. In contrast, relationships with neighbours or those at work might be almost unchanged. Although some mentally ill people develop persecutory ideas towards complete strangers, it was close family who usually were the subject of such feelings. Previously intimate relationships were an early casualty of the illness.

Clausen and Yarrow's research papers were published in 1955. They represent an attempt to understand the experience of a relatively small number of American women whose husbands had been admitted to a hospital for mental illness for the first time. The study was longitudinal and looked at men aged 25 - 60, who often had young children and family responsibilities. Although written forty years ago, and at a time when methods of treatment and attitudes were somewhat different to today, the study elucidates the women's feelings and experiences in a way that makes it extremely relevant. To my knowledge, there have been no subsequent studies that have covered this ground in such a thorough manner. Thirty three families were studied with a diagnosis of 'psychosis or psychoneurosis' (Clausen et al, 1955a:9). An attempt was made to exclude people defined as having a personality disorder or dementia. Though the diagnostic categories are not strictly comparable with current study, the data remain useful.

They noted that mental illness rarely begins with signs of madness 'in the guise of the popular stereotype of insanity' (Claussen and Yarrow, 1955a:4) and observed that the women did not view early signs as indicative of illness but interpreted it with the context within which it occurred. Bizarre behaviour or comments led to attempts to understand, and the boundaries of acceptance were stretched to accommodate the symptoms. The odd behaviour is attributed to an every day cause: stress, worry etc. Yarrow et al (in the same series of papers) observed that as the symptoms were rarely constant, but punctuated by periods of normality, the women fluctuated in their conclusions, at times feeling that something was very wrong and that "he should see a psychiatrist", and at other times feeling things had every day causes (1955:13).

Then things might settle down and the urgency for a referral too would ease. This again reflects the way in which women 'apply' a systemic model to family problems.

This difficulty and appropriateness of extracting the behaviour from its interpersonal context was a very familiar source of frustration and distress to people in the current study. People who manifest interpersonal tensions may not present these at an interview with a psychiatrist. What then is the difference between a domestic dispute and signs of a mental illness? Yarrow et al refer to the above process as an 'overlapping situation'. 'The wife is in an "overlapping" situation, of problem-not problem or of normal-not normal. Her interpretations shift back and forth' (1955:15). Contrary to professional myth, relatives in this study were not eager to recognise difficulties in terms of mental illness. "It's the very last thing you think of". Despite my own psychiatric training I did not readily apply a definition of mental illness to our difficulties. Although I recognised depression, the other pieces did not fit any commonly known diagnostic jigsaw. I believed that I suffered from an oversensitivity to psychiatric phenomena (created by reading too many academic journals). My definition of the situation oscillated. To use a psychiatric framework felt like an abuse of my own professional power within the relationship, and an approach that absolved me from blame. Although a particularly strong feature of the early process, this oscillation was never completely dispelled despite subsequent diagnosis and treatment. It could be reactivated by any party, by my partner, the psychiatrist (especially a new one) or by myself.

For others, the changes that took place were more dramatic. Mr C's wife became depressed after having an affair. Things became critical when she put drugs in her husband's tea to make him sleep. She then took an overdose and went to the river to drown herself. For these families the problems had been difficult but were almost manageable until some crisis occurred, after which admission usually followed. The crisis might be a life threatening event, or involve people outside the home, preventing its reabsorption into normal life. It also could involve bizarre behaviour or comments.

My partner had been depressed for some weeks and had felt suicidal. We had decided to try and get by, like we always did. There was no point in getting tablets, he had tried them before and they made him feel awful. He wanted "to be left to weather the storm". He rang me at work one afternoon. I knew there was something wrong and phoned back. He had felt so depressed all that day, he could hardly walk up the stairs. He had gone into our cellar to get a rope and was fighting an overpowering urge to hang himself. I said I'd better come home. I cried all over my papers and then phoned for someone to cover my on call duty. A colleague and I planned my approach. He suggested that my partner and I took control, before the services took control from us. I went home to take him to the doctor, knowing that if he didn't agree I would have to phone my colleague who would have come to section him. We went to the surgery and went in together. The GP said afterwards that we had 'inappropriate affect'. We had told the GP in relatively nonchalant terms that he was in danger of committing suicide. They dished out the antidepressants and phoned the psychiatric nurse to make a referral. I was told I should stay off work for the next three days in order to keep an eye on him. No sick note was available for this absence and I would have to use my leave. I suppose this is when I became a carer. Up till now I had put the depression down to every day events like losing his job but I could no longer do this. (personal caring diary, November, 1993)

Mrs W's son was sectioned when he was 21 and taken to hospital after he had screamed all night. This represented the actual crisis, but when she looked back she could observe a long slow deterioration over seven years. He had

been “very clever at school” but, only passed one ‘O’ level and also “ran away from home because of his problems”.

Mr R’s daughter had had problems since she was 14 and received treatment for anxiety. He felt she was probably just “a bloody minded teenager as she would argue with them and storm off “. Mr R said things really went wrong when she was 17. Her aunt was due to visit and she wanted to ask the aunt whether “people could walk through walls”. Mr R said he “knew then she had a mental illness.”

Mrs M’s brother became unwell at 16. He became very religious. The family felt he must have a vocation (they incorporated his beliefs into a framework of normality) then he began to believe he actually was Jesus and would stay awake all night. Mrs M referred to what she called the “strange symptoms” and when her brother began to say he could see donkeys’ heads on people, she made the connection with a patient at the surgery where she worked. That patient was diagnosed with schizophrenia. A nurse came and talked to her brother, he said it was anxiety but Mrs M felt it “was really bad, and that he was like the people she had seen coming to surgery for treatment for schizophrenia.”

Some relatives had already had experience of mental illness in their own family, and used this as a bench mark for evaluating the problems. Mrs D had cared for her father-in-law. He had schizophrenia and used to sit in the chair a lot and would not get washed. She said she had seen people “who were bad with their nerves”, so when her daughter began to shake a great deal and became convinced that she had invisible marks on her face, Mrs D knew there was something wrong. Mrs D, like many carers, would not go into detail about her daughter’s symptoms. She conveyed to me that things had been very difficult but added that “people did not really want to hear the details.” She applied this to me even at a time when I was her family’s social worker. Carers may be reticent to share their very painful experiences. This may be a form of denial but also due to a fear that the details may disturb other people and drive

them away. Experience of similar problems can sensitise professionals to what might remain unsaid and they may be able to help by 'normalising' such material.

For Mrs EE, her experience of her mother's schizophrenic illness meant she was able to recognise her youngest son's problem almost instantly. At 17 he began to threaten his parents for money. She recognised some quality in his behaviour that was characteristic of a problem like her mother's. "I knew it was the end of life as a normal person, I knew what was happening." Few relatives, if any, could have been described as embracing a psychiatric definition at an early stage on inadequate evidence. For carers in this study, suspecting that the difficulties were related to mental health was the result of a life-threatening event; prolonged problems, in which relatives oscillated in their conviction that there was 'something wrong'; or some event that was clearly abnormal, and allowed them to 'diagnose' a mental problem. Children who have grown up with parents who have chronic severe mental illness, have little means of recognising that their parent is different in some way, and that they face problems others do not encounter. Mrs AA said that she grew up believing the "the noise, the shouting, the language were quite normal" but feels that it was "different for her older brother and sister. They had known their mum before she became ill and had seen her change."

Mill's study suggested that relatives 'held on' and tried to cope at home, often for many years before seeking help. Often this 'help' was forced on them when they could no longer contain the problem. Mills found that families had coped on average for six years before seeking admission to hospital. He noted that in more than half the cases the admission was sought by people outside the family: the GP, police, a social worker or the neighbours. Although people admitted by a carer's request tended to be very ill the family still experienced considerable guilt and ambivalence at what they felt they had done (Mills 1962:87-88).

People interviewed found it very difficult to anticipate what the future held for them. Little or no indication was given by any professionals involved. The group who supported someone with dementia however did face the future with an understanding of the prognosis, even if this was difficult to accept. The carers of mentally ill people however seemed to have been left in some form of limbo. Perhaps, in an attempt to avoid giving a very negative prognosis, especially when a user might be just 18 or 19, the professionals avoided giving any information at all. Carers were left to piece their jigsaw together, trying to make some sense of all the strange, frightening things that happened.

Getting Help

Recognising that they have a *problem*, the carer is now faced with finding help. When a carer decides to seek help there are a range of options and these include contacting the family doctor (who might seek the opinion of a specialist), contacting a community mental health centre, referring the matter to social services, or talking to friends and relatives. For virtually all the families the GP appeared the obvious point of contact. Butrym and Horder note that people take a wide range of problems to their family doctor as 'not all people consulting doctors have any disease. Patients consult sometimes because they are anxious, depressed, lonely or in conflict with another person' (1983:11). Given the ambiguous status of the problem, illness but not illness, social yet not, the GP would appear ideally suited to provide help. This choice would be further supported by the reassurance of confidentiality which friends could not be relied on to observe. Carers did not want to seek help, it would have been better if their relative had 'seen someone' or better still if the problem had just gone away. Carers were often not sure who the problem belonged to and their relative could offer them no assistance with this.

No one in the current study mentioned approaching social services, or a community psychiatric nurse, initially. Such approaches were often made later, when the carer was more familiar with the *system*. As the problem tended to

emerge gradually, perhaps culminating in a crisis, it was difficult to ask people about *the occasion when they first sought help*.

People with Dementia

People whose relatives suffered dementia recognised that the problem developed stealthily. When one looked back over a period of years, they could recognise a deterioration in their relative's abilities. When you live with someone every day the changes are less easy to detect. Indeed the slowly developing symptoms are one of the diagnostic signs. Pitt says 'most definitions of dementia emphasise its insidious onset'(Pitt, 1982:39).

Mrs G's mother started to wander. Her mother would be driven home after tea and then set out again to find her daughter's house at 11.00 pm. She would wander the streets and be unable to find her way. Mrs G went to their GP who immediately offered a referral to a psychogeriatrician. Mrs G found the GP's attitude insensitive and said "He didn't give two hoots". Mrs G said she had expected understanding as well as action. For everyone involved recognition of disturbed behaviour in their loved ones is a painful experience which carries a psychological threat. People caring for those with dementia seemed familiar with terms like "dementia", "Alzheimer's" and of the possible significance of an older person becoming forgetful. These symptoms have been absorbed into popular culture and this may allow families to discuss their presence more easily than signs of schizophrenia or bipolar disorder. Mrs G waited for the referral but said the GP had forgotten, and she had to make a second visit. She was unhappy that the GP appeared to regard the situation with indifference. When the psychogeriatrician did see Mrs G's mother she offered an early home visit and sent a specialist nurse (CPN). The nurse in particular was felt to be "very, very good".

Mrs H sought help because her brother, a man in his seventies, underwent a "change in personality". This happened over a period of two years and culminated in him wandering during the night. Mrs H had a family friend, who

was a geriatrician, and he organised a diagnostic scan, to confirm his suspicion that Mr H was suffering from dementia. Although the changes in behaviour were painful for Mrs H the path towards help could be described as smooth. Having a doctor with appropriate knowledge clearly assisted the process, but others in the current study also found doctors prepared to talk about the presence, and implications of dementia at an early stage. This was not the case for severe mental illness, especially schizophrenia.

Mrs I is a lady in her 60s, and became confused over a period of three to six years. When her husband had a slight stroke, she seemed to “get worse over night and couldn’t even make a cup of tea anymore”. Mr I felt positive about all the help he had received. Initially he went to his GP, she told him “it is probably Alzheimer’s disease” and explained what this meant. This was done with kindness which Mr I appreciated. A referral was made to a geriatrician who confirmed the diagnosis of Alzheimer’s disease. Mr I was told of the diagnosis and also about the implications for the future.

Mrs F’s husband was only in his 40’s when he became ill. A point in life when he was working and supporting two teenage daughters, not a time when one is expected to experience dementia. At first he became forgetful. Some months later Mrs F felt she must see the doctor as her husband was dismissed for leaving work early. She had noticed how withdrawn he had become, and had tried to look for obvious causes such as problems at work. She had tried to talk to him, but he didn’t feel there was anything wrong. In fact when she did visit the GP her husband had already been to ask for a sick note and must have had some insight into his illness. The GP told her immediately that “there was no help for him and that he would end up in a psychiatric hospital”. Mrs F’s husband was diagnosed as having an organic brain disorder of presenile onset. Its exact nature remains a mystery, despite post mortem study. It can however be placed within the category of dementia.

These cases are representative of my own clinical experience of working with older people. Families are frequently forced to seek help, as the person cannot

recognise their problem and are too confused to take action on their own behalf. Fears for the person's safety become paramount and approaches to the GP are felt to be appropriate. None of the carers in the study was refused advice or asked to seek their relative's consent before the GP would talk to them. It was clearly understood that although the individuals were adults, their illness prevented them seeking help for themselves. This practice contrasts with that of professionals towards carers of people with schizophrenia or bipolar disorder.

Help for Families of People with Bipolar Disorder and Schizophrenia

The situation was different for the carers of people with schizophrenia and bipolar disorder. Those whose relatives sought help themselves could be described as being fortunate. One young woman falls into this category and she is quite unusual. Mr R says his daughter "soaks up medical treatment". When she is ill she would rather be in hospital and she will cheerfully accept any medication that is prescribed for her. Other sufferers did go to see their doctor, but the help they received was inappropriate in their carer's opinion. Mrs D and her husband said their daughter's "nerves were bad". They were angry that the GP didn't offer any medication but told her "to go away and have a baby". The GP is in a difficult position, they may not wish to make an early (psychiatric) diagnosis, especially in cases where the diagnosis carries a powerful stigma. In such circumstances light hearted reassurance may feel more appropriate. Getting a dismissive response does have other consequences however, and the carer and their relative can feel they have exhausted medical advice and be left without an avenue of help during subsequent crises.

In the sample of people with schizophrenia or manic depression there were no examples where a *carer* had sought help from the GP and felt they had initially received a positive, helpful response. The impression was one of frustration, having to fight to get someone to act and subsequently of anger on the part of

both parties. Mrs CC's husband had never suffered from mental health problems but began to complain of headaches, chest pains and insisted that his wife was having an (imaginary) affair. The GP sent him for numerous tests for physical ailments, including a scan, but all proved negative. Her husband did not accept he needed treatment for a mental health problem and was unwilling to see the GP on this basis. Mrs CC felt she had to get help for him, his behaviour and personality altered, he argued with people he had been close to, and his self care deteriorated. Although the GP had initially told Mrs CC that he felt her husband had a mental health problem, he later denied this. He was not prepared to discuss her husband's condition with her as the matter was "a relationship problem". After several difficult years, her husband left home and this meant that, legally, Mrs CC had no further right to be involved in his welfare.

The Family's Right to Help Under The Mental Health Act

There is a legal option open to close relatives who feel that their family member needs urgent psychiatric help. The nearest relative, as defined under Section 26 of the Mental Health Act 1983, can ask the local authority to direct an Approved Social Worker (ASW) to assess the prospective patient with a view to admission to hospital. When Mrs CC's requests to her GP fell on stony ground she pursued this legal avenue. She remains angry at the response. The ASW discussed the case, but explained that Mrs CC was no longer the nearest relative as she was separated. Ms CC found this difficult to accept, she *felt* married and that her husband had left her because he was *ill*. She was able to offer over 20 years evidence of a stable, close relationship to support this. Undeterred, Mrs CC's daughter (now the nearest relative) made a request for a mental health assessment. A reply was sent to the family some weeks later. The ASW had spoken to the GP, but he felt unable to discuss the confidential welfare of his patient, and the ASW felt satisfied that no further action was necessary. Mrs CC and her daughter felt bitter, that this legal right was a sham and lacked any real power. They also suspected that the GP might be unwilling to impose psychiatric treatment on a well respected man,

who appeared to be holding down a responsible job. One was aware of the GP's dilemma. As I listened to Mrs CC I could never feel completely convinced that her definition of her husband's behaviour was appropriate. I was conscious of a (professional?) tendency to consider what she told me with some scepticism, while sympathising with her distress. Ironically I noted that same attitude from professionals as I told them of my husband's behaviour which I considered to be symptomatic of mental illness.

Traditionally the inclusion of this observation may have been regarded as inappropriate and rather subjective. As a professional conducting research it would have been all too easy to miss what is a fundamental issue for carers. Reflexivity requires that one reconsider how events are understood by those involved and by the researcher themselves. It seemed that the GP would not accept an approach from a family member about a relative's mental health, yet if she had been married to someone suspected of having dementia her concern would have probably been accepted.

A Family's Relationship with their GP Breaks Down

Mrs AA's mother is diagnosed with 'schizophrenia' and has been ill for 34 years. Mrs AA was only a child when the problems began but she was able to tell me of her recent attempts to obtain help from their GP. She described her mother going through cycles. "She tends to take medication for four years and stays well. She reduces her medication, reduces it again, until she does it one time too many. She is all right for a while then she becomes ill again." During such a period Mrs AA felt her mother needed to be referred to a psychiatrist but the GP disagreed. Mrs AA persisted in making requests and then her entire family were removed from the GP's list. She added that GP's are not obliged to give a reason for this decision. Her mother was not well enough to understand what this action meant. Mrs AA obtained a new GP for her mother, but her mother "got rid of him as she wanted her old one back." Naturally Mrs AA was unaware of the position and her mother was discharged from hospital without a GP to monitor her. There is suspicion that some GPs may be less than

enthusiastic about accepting people with serious mental illness onto their lists. Fund-holding may have intensified the position and research is needed, especially around the circumstances under which GPs should be permitted to remove vulnerable people from their lists. Although living in the community Mrs AA's mother lacked the skills to obtain medical care for herself. The position for mentally ill people, who do not have the support of relatives and have lost touch with their Care Programme Approach key worker, is particularly worrying. Mrs AA is a confident woman but is angry at having been "punished" for her persistence. Some carers in the current study, supporting relatives diagnosed with severe mental illness, became more persistent in their requests for help from GPs, but this may lead to a strong negative reaction rather than to help being provided.

GP's and Confidentiality

Mr and Mrs V's daughter has been ill for some years now and the family continue to seek help. At times they have taken tape recordings of their daughter screaming to the GP. Their daughter suffered one extremely traumatic removal to hospital, and has been terrified of professionals ever since. She will not visit the GP, or see a psychiatrist at out-patients, but the psychiatrist will not help unless she will attend for an appointment. Mr and Mrs V have suffer extremely distressing and aggressive behaviour through their daughter's problems and it can be easily argued that they have needs of their own, which the GP could be in a position to address. Their needs stem from the pain of watching their daughter being tortured by her experiences. I have chosen this emotive expression because I can think of no other way to describe her symptoms. Mr V took the tape into the doctors and asked him to listen. He said "Yes, it's beginning to form a pattern" but would not comment more and made no offer of help. I will return to a discussion of confidentiality at a later point. One can only assume that the GP's motive was a concern to protect his patient's confidentiality, as it would be difficult to argue that she did not need treatment.

The GP-Carer Relationship

In order to understand the nature of the relationship that the respondents experienced with their GPs, one must consider patients' experiences in consulting regarding non-psychiatric problems. Miles notes there is a substantial literature about consultations between patients and doctors. More recently attention has focused on the way doctors respond to female patients. Researchers have noted that doctors do not treat everyone in the same way but classify patients according to whether they are 'easy' to deal with, are 'bad' or a 'problem' (Miles, 1991:154). Indeed, when 453 doctors were asked, in a postal questionnaire, to describe the characteristics of patients who 'caused the least trouble' or the 'most trouble' some 93 per cent felt able to reply.

The results showed that women patients were widely held to be 'more trouble' than the men and that patients presenting the doctor with organic, physical and treatable diseases were considered less trouble than those who complained of emotional and psychiatric problems (mainly women) and those with chronic diseases (Miles, 1991:155).

These findings may assist in interpreting my experiences as a carer. On the first occasion that my partner *and* I made an emergency appointment with the GP the response was very helpful. The GP took time, listened, showed concern, and prescribed medication (personal caring diary, Nov. 1993). In this case the patient had sought help in his own right, and I had showed appropriate concern, but not interference, by accompanying him. The problem was new, acute and hopefully short term. My partner had demonstrated motivation by seeking treatment and was 'rewarded' by a positive response.

Although psychiatrists soon became involved in almost every case in the study, GPs continued to play a central role. Once discharged from hospital the GP is responsible for the patient's care, and he or she was usually the only real professional crisis service available after 5.00 pm. It was in such circumstances that I twice phoned the GP on call, after hours, during what I

perceived to be a crisis. This was after my partner had had a period of hospital treatment and a diagnosis, but was continuing to experience problems. It is inevitable (and perhaps not undesirable) given the focus of the research that I will present my side of the story. I have attempted to be as honest and self-searching as possible. By November 1994 I was also clinically depressed and accepted the consultant's advice that I take anti-depressant medication. I had had a history of mild but significant episodes of depression, but it was 19 years since I had required medication.

My partner had been suicidal and depressed again during my half term break, and had spent one night in hospital in a medical ward, due to the shortage of psychiatric beds. The consultant wanted to change his anti-depressant feeling that there was no response. My partner quickly became irritable and morose. Feeling unprepared to try to cope with this level of symptoms, I phoned for the doctor on a Sunday afternoon. Realising that hospital might be imminent my partner controlled his presentation admirably. The GP stayed an hour and talked in a reassuring and relaxed manner. He commented on the excellent speech my partner had made at a dinner earlier in the week (if only he had known what was going through my partner's mind) and then turned to me. He explained that he had stopped at the surgery to collect both sets of notes. "I feel I have two patients here and at the moment you look the worst." (personal caring diary, November, 1994)

As soon as the GP had gone my partner told me he had put on an act to convince the GP that I was "medicalising" his behaviour. How could I blame him, given the circumstances, where he might have been forced to go into hospital? The experience was crushing and almost as upsetting as coping with my partner's depression. I continually searched my conscience, in case I was guilty of a major distortion of the circumstances. There was also the realisation, that should we need help again, there would be no-one I could

trust to call. I vowed to avoid contacting the GP again. From this time on, in my opinion, my judgement appeared to become suspect in the GPs' eyes, despite my partner attempting to set the record right. Their response was essentially one of 'patientization'. Ahmad uses the term 'clientisation', to describe the way in which social work disempowers and controls black families. Unable to hold a dialogue with black families that is characterised by partnership, black families are pathologised (Ahmad, 1990:7). 'Patientization' appeared to allow the GP to frame events in a way that felt intelligible to him, I experienced it as a betrayal and an abuse of power.

This process extended to the dealings of medics with other carers in the sample. Mrs U supports her 20 year old son diagnosed with unipolar mania. At times she felt overwhelmed by the emotional impact of his illness. She felt that doctors stressed the importance of confidentiality but that she wanted help for the *whole* family, as they had all been affected and needed help to cope. This was not offered but the GP referred Mrs U to a psychiatrist in her own right. Mrs U has since had 'therapy', involving an examination of her relationships in early life. It seems that the only way the system appeared able to respond to her request for help, was to address her individual pathology, totally ignoring its context. The system did not seem able to relate to her distress except by creating another patient.

Although I was determined to cope without GP help it was inevitable that there would be subsequent crises given the severity of the illness.

During December 1994 my partner was severely depressed, and as he did not want to be in hospital was having out-patient ECT. Christmas was difficult but on Boxing Day evening he suddenly announced that he wanted to "strangle me". This was out of the blue, and without any provocation. Then he told me that if I called the doctor he would "go for him too". I sighed and sat on our bed. I knew that I really couldn't leave this and just get into bed to go to

sleep with him that night. He also had a strange twisted expression on his face. I calmly told him he probably had a mixed affective state and should have anti-psychotic medication *now!* I pleaded with him to call the doctor but he wouldn't, so I phoned the elder GP on call. He arrived soon after and I pushed my parents and son into another room. The GP talked about "Christmas and family rows." My partner suddenly jerked in the chair and he told the GP how he actually felt. (He told me later he was unwilling to humiliate me by lying this time). I had suggested an injection over the phone and my partner accepted this willingly. I told my parents that "Christmas appeared to be over" and went upstairs to cry. What would I have done if my partner had not felt sorry for me and decided to come clean? (personal caring diary, December, 1994)

Being Believed

Relatives seeking help were desperate to be believed by professionals. At times even if nothing could be done, being believed could make a tangible difference. Being disbelieved did not seem to relate to the carer's social class, educational level or forcefulness. Even the most articulate carers, who might be professionals outside of their caring role, spoke of having their opinion ignored, even ridiculed. Mrs L's sister is in her 40s and has had periods of illness over 20 years. When she begins to deteriorate Mrs L can recognise the signs but "staff at the day unit will insist she is fine." Mrs L says she has to go and see them to explain that her sister is not coping, isn't cooking, and looking after the family. However, she feels "they don't think I'm telling the truth." Carers who had had this experience feel frustrated and can not understand what professionals feel their motive for lying or exaggerating would be. There are several possible explanations for professionals' attitudes: that carers describe symptoms in order to have relatives admitted to hospital; that carers pathologise their relative's behaviour, in order to scapegoat them for interpersonal problems, or that relatives are too close emotionally to the patient to make objective judgements. We have seen that most carers are reluctant to

allow their relatives to be admitted to hospital, and do not seek this option, unless they conclude there is no other answer. Carers of people with severe mental illness were not afforded the credence given to supporters of Alzheimer's Disease sufferers. Implicitly, the problems caused by the frequent lack of insight shown by people with bipolar disorder and schizophrenia were shunned. Carers received negative responses to their approaches to GPs, and Social Workers.

Not only did they receive bland unhelpful responses but also very angry ones. Carers were maligned for interfering and it seemed that though mental illness is superficially spoken of by professionals as brain illness, it is responded to as family dysfunction. One of the signs of such systematic pathology is the inappropriate behaviour of family members seeking help for a relative's alleged mental health.

Carers and the Role of GP's

Although policies have moved towards informal care for the severely mental ill, the attitudes of some professions have not adjusted to reflect changing practice. Jill Pitkeathley of the Carers' National Association noted that "carers and GP's are natural allies, GP's provide 90 per cent of community care" (Yee and Blunden, 1995: 6). While carers may believe that talking to the GP is the appropriate "channel for gaining access to local services" Yee and Blunden observe that GPs do not feel that they should have to support people with non-health (ie social or emotional) needs, especially when they are already overburdened (1995:6-7). Although of relevance to the new health market, the division between health and social needs can be of irrelevance to people using services. Indeed it may be argued that the boundaries reflect power struggles between budget holders and rival professions, rather than a conceptualisation that has meaning for people experiencing problems.

A project conducted in Sutton, to develop the recognition of carers and their needs by GPs, led Yee and Blunden to conclude that although GP practices

recognised the theoretical benefits of supporting carers, they were unlikely to put this into practice. There were concerns about confidentiality and that they were not paid for supporting carers. Given their level of responsibility, and status as budget holders, GPs would not be seeking additional responsibilities. They add that "general practitioners themselves are seen as precious, highly skilled technicians, whose job it is to identify and arrange treatment for medical conditions. The emotional and social problems which carers experience do not fit easily into this model." (Yee and Blunden, 1995:21) GP's are grappling with new pressures brought about by funding holding, and by their involvement in caring for chronically ill people, now in cared for homes in the community (Collier, 1995). GPs may be aware of the requests from carers for more support but feel that "they can not be expected to take on much more work". (1995:823)

Given their crucial role in accessing beds, prescribing, and providing crisis cover, the GPs have a very important role to play in the support of severely mentally ill people living in the community. Unfortunately it would appear that they are unable to meet these needs when presented by family carers. I have attempted to look at literature exploring GP's perceptions of severely mentally ill people and their carers, but have found that (to the best of my knowledge) the area is poorly researched. I am aware of psychiatrists currently seeking funding to explore this issue. In seeking help on behalf of their relatives carers find that GPs are over-burdened and that their practice has not extended to incorporate family carers as partners rather than as patients who threaten to challenge confidentiality between the doctor and the person who is allegedly mentally ill. As the GP is the principal gatekeeper to other health services and the only real 'out of hours' service, this failure to respond to carers in crisis represents a fundamental flaw in the community mental health system.

Chapter Five

Getting A Diagnosis

Diagnosis is both a medical concept and an event, and its content, or its absence, can have profound consequences for the patient and their family. It can be a passport not only to obtaining hospital care, but to getting a community nurse, a social worker, a place in day care, benefits, and to being able to articulate the nature of one's problems. I shall attempt to look at diagnosis as practised in mental health care, and at the consequences of that practice for families.

The Role of Diagnosis in Psychiatry

Diagnosis may be a priority for doctors and of interest to other professionals, but it is also closely paralleled by a basic human need. People experiencing ill health feel the need to understand what is happening to them. They will search for causes: 'Have I caught flu because I have been tired lately and got wet in the rain?' 'Have developed this problem because of my genes?' There may be no clear answers to these questions, but it appears an essential element in accepting and adapting to illness. Studies of people experiencing minor psychiatric problems illustrate their attempts to frame the onset of illness in such terms. The theories that professionals have about the causes of illness may be quite different to those held by lay people. This is probably especially relevant where 'scientific' explanations of aetiology are incomplete or unconvincing, as in the area of mental illness.

Angermeyer and Klusmann investigated the causes of functional psychosis as viewed by patients and their families. They were interested because patients and family carers will be influenced in the acceptance of treatment (medication?) by their own definitions of the problem. 'Medical sociologists in

particular have emphasised the importance of the patients' construction of their own aetiological models in their attempt to deal with their illness' (Angermeyer and Klusmann, 1988:47). Almost all the patients and family carers had developed theories of aetiology. These were often psychosocial rather than biological, with people diagnosed with schizophrenia adopting 'esoteric' reasons or blaming family influences.

Brown and Harris' study of women experiencing clinical depression described the women's attempts to identify causes for their symptoms and to put their illness into a framework they could relate to (Brown and Harris, 1984). This often included trying to isolate a stressful event that coincided with the onset of depressive feelings.

Doctors make diagnoses in order to classify signs and symptoms, but also in order to decide treatment. Psychiatrists follow the model used in wider medicine and attempt to isolate signs and symptoms indicative of a syndrome.

Black's medical dictionary describes diagnosis as 'the art of distinguishing one disease from another, and is essential to scientific and successful treatment' (Macpherson, 1992:158). However, where other branches of medicine can rely on tests to aid diagnosis, eg the examination of pathological changes at the level of the cell, the psychiatrist in the case of schizophrenia and bipolar disorder must rely on an examination of the patient's mental state (Gelder et al, 1993:47). Criticism of the reliability of diagnosis has been influential in causing some users to reject any 'labels' psychiatrists may have tried to impose on them. Lawson, in a talk to mental health professionals and users at Durham University in 1995, noted that he has attracted a variety of labels including schizophrenic and manic depressive. Many also add that they have been told that there is nothing wrong with them by one doctor, and that they have an illness requiring compulsory treatment by another. Despite the criticisms, psychiatry stresses the need to classify disorders as a tool for discussion, research, and the evaluation of treatment (Gelder et al, 1993:78). Gelder et al note the sociological criticism that psychiatric diagnoses do not help one to

appreciate the individual's problems, and that they are inherently stigmatising. They suggest, however, that the stigma does not flow from the diagnosis per se, and is a separate issue. On the other hand, much can be gained from the accurate classification of mental problems, but Gelder et al add that this should not eclipse the understanding of individual difference (1993:78).

This study is also structured through medical classification because medicine continues to influence the way people are responded to particularly with regard to mental ill health. Diagnosis can determine how individuals think of themselves and how they are perceived by their community. People diagnosed as 'schizophrenic' or 'manic depressive' are likely to be responded to in terms of these labels. The media regularly feel able to comment on the activities of 'schizophrenics' as if such people constituted a homogeneous group.

The Sociology of Illness

Morse and Johnson have highlighted the contributions of sociology to the study of health care. They note that professionals who have experienced severe illness and medical care, have found it necessary to write about their experiences 'in order to "jolt" their peers into a new kind of awareness, when interacting with patients' (Morse and Johnson, 1991a:1). Such accounts, they feel, lack scientific status and are anecdotal. Given this weakness, sociological studies (presumably of larger samples), can offer more convincing data about the experiences of illness.

Accusations of material being 'subjective' or 'anecdotal' may be well founded but they can also be stock responses to criticism of the status quo. If these anecdotes are isolated then they pertain to the experience of individuals. While true, they lack grounds for supporting changes in practice. On the other hand, we may learn a great deal from hearing a number of such accounts which make similar statements. Larger studies may have the benefit of size and the support of probability theory but may fail to portray the depth of experience of the individual. I would therefore suggest that data from this study is more than

merely anecdotal. It should be viewed carefully and where respondents verify one another's viewpoint or experience there may be evidence of regularities, worthy of further investigation.

People experiencing discomfort, or symptoms, engage in the process of trying to understand what is happening to them. Morse and Johnson describe a phase of uncertainty and, in this stage, the individual detects or suspects signs of illness and attempts to make sense of these symptoms by determining their severity and meaning. Those closest to the ill person (usually family members and friends) observe that the sick person is unwell, but these observations may lag behind the experience of the ill person (Morse and Johnson, 1991b:317). They describe their theory as an illness constellation model. It contrasts with the medical model which focuses on symptoms, and the 'adaptation' model which analyses illness behaviour. The illness constellation model acknowledges the social context of illness behaviour, *and* looks at the part played by close family and friends (1991b:318). It is this approach that is more useful to this study, recognising the role played by carers and the limitations of focusing on the patient in isolation.

Deciding When to Seek Advice

There are significant differences between severe mental illness and a range of so called physical illnesses. An examination of accounts of physical illnesses serve as comparative models. Johnson observes that the patient will first try to 'normalise' the emerging symptoms: she offers the example of heart pain, and describes how 'in every case past events and experiences were used to make sense of the initial symptoms' (Johnson, 1991:19). Patients considered how they felt, and related this to previous experience, trying to convince themselves they had a cold, or had pulled a muscle. It is against this context of uncertainty and confusion that a decision is made to seek advice. Their hope is simple, that the doctor will tell them what is wrong, ie. make a diagnosis, and prescribe an effective treatment. The doctor may even be able to reassure them that nothing is wrong at all.

People who discover a tumour, for example women who find a lump in their breast, often experience profound anxiety during the time before they contact their doctor. Having decided to visit the doctor the process may move quite swiftly towards identifying the nature of the tumour. Fallowfield (1992) notes that this period is characterised by the use of diagnostic tests and then the woman will be provided with a diagnosis and treatment plan. There are, however, occasions when the diagnosis is *not* shared with the patient.

How does this process relate to the experience of carers of severely mentally ill people? Not all patients will experience symptoms, yet some are clearly conscious of problems and do seek a diagnosis. My partner told me that he had been in a psychiatric hospital for a month some years before I knew him. Deciding to enter hospital for psychiatric treatment clearly marked a rubicon for him. It symbolised a recognition that something was 'wrong', and that he wanted it dealt with: "I thought that at last I would find out what was the matter with me, but they didn't seem to know". For him, at that time, the upheaval of admission seemed to have lead nowhere. He felt that he had been denied a diagnosis and that the outcome was unsatisfactory.

Diagnosis and Dementia

The carers of people with dementia were able to demonstrate a fairly rapid movement, from making a decision to seeking advice, to obtaining a preliminary diagnosis and having this confirmed by a specialist. Although the nature of the dementia could not be given specifically, the question of alternative diagnoses and of damage to the brain, could be supported by diagnostic tests.

Mrs F visited the GP independently about her husband's ill health, and was provided with information that her husband had an incurable, organic, psychiatric illness. The psychogeriatrician told Mrs G that they "thought it was probably Alzheimer's". Mr I was told of his wife's diagnosis in a provisional form by the GP and this was confirmed by the consultant. Mrs H was told of

her brother's diagnosis after he had seen the specialist who sought supporting tests. One can not doubt the anxiety and confusion that must have been present with these carers for some time before they decided to get advice, but their request was not considered inappropriate by the doctors when it was made. Although there is evidence outlining the presence of insight and hence intense anxiety felt by sufferers of early dementia (Pitt, 1982:46), their inability to seek help for themselves is generally accepted, because of the inevitable absence of insight as the illness progresses.

Diagnosis and Relatives in Mental Illness

This common sense approach adopted in the diagnosis of dementia, and towards family carers of people with dementia, does not appear to be extended to schizophrenia or bipolar disorder. The reasons for this need to be given further consideration. Throughout the study, the provision of a diagnosis appeared haphazard. If it was provided, this appeared more related to the personal style of the specialist than to any well considered procedures.

Some people had been ill for a period of years and had experienced several admissions to hospital, received community and out-patient care, yet had never been offered a diagnosis. Diagnosis for others seemed better understood as a process rather than an event. Mrs A's daughter had been admitted to hospital three times (for schizophrenia), but Miss A and her mother were told of the diagnosis in a perfunctory way during a pre-discharge meeting. The psychiatrist later told me he had told the family of the diagnosis at an earlier time, but they "had not taken it in". Mrs A's daughter was to be given a modern anti-psychotic medication, clozapine, which requires regular blood monitoring. Clozapine is only registered for the treatment of drug-resistant schizophrenia, or where the patient has had severe side effects from other drugs, and therefore a diagnosis *must* be given. The treatment carries risks and patients are expected to give informed consent. Clozapine 'can cause agranulocytosis, a serious and potentially fatal blood disorder which causes damage to the bone marrow' (Lacey, 1993:123). Although it could be suggested that Mrs A and her

daughter had simply tried to deny the diagnosis given at an earlier point, there must be concern about the timing and appropriateness of the information given. Accepting the knowledge that oneself or a close relative is suffering from a severe, long term and stigmatising illness is difficult and entails considerable adjustment. The advent of treatment with clozapine appeared to be associated with a new 'honesty' concerning the diagnosis.

Mrs N was also aware of her son's diagnosis. He was being treated with clozapine and hence the family was aware of the diagnosis, but this did not appear to have been provided *only* when clozapine was being considered (as in Mrs A's case). Mrs N's son appeared to be one of a number of young (early twenties) patients who were offered a name for the illness during their first or second stay in hospital. Mrs N seemed quite comfortable talking in terms of schizophrenia, but made it clear that it had taken time to adjust.

Mr R's daughter was sixteen when she became ill. She developed strange ideas which Mr R recognised as mental illness. He felt that it was very unusual to have received a frank and rapid diagnosis in 1980. Apparently, the doctor took just 'ten minutes' to diagnose and said he "was pretty sure it was schizophrenia".

Morse and Johnson (1991b) note that relatives' perceptions may lag behind those of the person with physical illness and that 'carers' may not be aware that something is wrong, until the sick person advises them. For many who are close to people with severe mental illness the situation is actually reversed, with the carer suspecting that there is something wrong, rather than their relative. In many cases, the relative may insist that they are well even when the carer has come to believe that behaviour is severely disturbed. In other cases, the relative may feel unwell and seek help, but this may be for more limited reasons than those perceived by the carer. As the symptoms are felt throughout the family, and especially by anyone very close to the allegedly sick person, such family members will experience confusion and a need for an explanation. It can be argued that people experiencing symptoms experience

both physical discomfort and the emotional unrest of knowing that something is wrong, and have a right to the clarity that medical information can offer. This right is mirrored by the need of the carer to understand what is happening and what this means for their future. At present, medical convention does not acknowledge a right to knowledge about the medical affairs of another.

Telling the Patient

It appears that in the area of severe mental illness some doctors continue to avoid revealing the diagnosis to their patient, let alone to their family. Goldie notes that even with physical illnesses some diagnoses are more easily provided than others, and that it appears easier to discuss heart disease rather than cancer (Atkinson, 1989:21). Schizophrenia is not a palatable subject, and it may be tempting to avoid its discussion. This can be framed as concern over the effect on the patient's welfare (1989:21). There may also be concern expressed about the stigmatising effect of the label and a resort to using a euphemism such as a 'breakdown' (1989:22). However, a failure to tell does not necessarily ease the patient's fears and many will have suspicions. Some doctors like to wait for a second episode before diagnosing, but it may not be justified to wait for a recurrence in order to confirm a diagnosis, as this can leave the sufferer in a state of apprehension. Carstairs et al (1987:59) note that family and patients may well have suspicions about the symptoms and could accept an honest diagnosis framed in provisional terms. After all this courtesy is extended to people with physical illnesses unless there are clear indications that the patient would prefer to remain ignorant.

The Search for a Diagnosis

Some carers and their mentally ill relatives gathered information on an ad hoc basis with a deterioration in the prognosis at each progressive stage. Mrs E's forty year old son had been ill for a number of years and had been in hospital on several occasions. Mrs E's understanding of the diagnosis was in terms of 'depression', and she remarked that the first she knew of a diagnosis of 'schizophrenia' was that the consultant had begun to write it on the sick note. She had been quite taken aback by this, "as he had always written depression before". This change in diagnosis, if that was what it was, or at least declaration of the 'true' diagnosis, was not given in the context of information, counselling, or support. Although, as the family social worker I was able to talk through the consequences of the diagnosis, I had not been aware of any decision to inform Mr E or his mother that he did not suffer from depression alone. The power of the term 'schizophrenia' should not be under rated and it is an expression that should not be used carelessly, without consideration about its impact.

Some carers embarked on a 'diagnostic quest' (Corbin and Strauss, 1988:31), in isolation from their relative, the relative being convinced that they did not need advice, or any need for information being insignificant, when they were fighting for mental and physical survival, often against perceived supernatural enemies. People who feel that their minds are under attack from alien forces are not motivated to seek a diagnosis for *their* illness. One woman who felt that her home was under attack was dismayed that the professionals would not believe the truth and preferred to section her. It was some days later, after treatment with anti-psychotic medication, that she felt able to re-examine her experience within an illness context. At the time she had sought help, not for psychosis but to protect her from danger.

Carers embarking on a diagnostic quest felt the need to understand the changes in their relative and to have an explanation. They played at detective,

supplementing with reading what people told them. Once again, because of the nature of the subject, they were limited in who they felt able to approach. Mrs M realised that her brother had schizophrenia because she was able to compare his symptoms to those experienced by other people who came to the doctor's surgery where she worked. She tried confronting the doctor, but he insisted it was 'anxiety'. Mrs M asked her own doctor. This doctor was prepared to state that the diagnosis was schizophrenia. He felt that 'the symptoms were irrefutable and recommended that they seek a psychiatrist's opinion privately'. Where a doctor was prepared to discuss the case frankly, relatives were always grateful. The family found the money for a private opinion, they had to, Mrs M said "we were desperate".

Mrs L also embarked on a quest but the circumstances were different. Her sister knew she was described as having manic depression, and Mrs L was able to read up about this in the hospital library, where she worked. Mrs L said no one actually told *her* the diagnosis formally, nor discussed its implications. Although the doctors at the hospital described Mrs L's sister as being bipolar, one GP at least privately added "she's a schiz really". Unable or unprepared to use the more menacing term, manic depression was frequently used as a euphemism for schizophrenia in the geographical area of the study. Although unpleasant, it lacks the violent connotations associated with the term schizophrenia. Professionals never discussed the rationale behind this, as the decision to apply diagnostic terminology rested wholly with the doctor.

Finding out by Default

Mrs P's son is severely ill with 'schizophrenia' and she uses the term comfortably, but during our discussion it was never clear how she learned of the diagnosis. When Mr P became ill, the emphasis was on responding to the symptoms and this over-shadowed any opportunity to offer a diagnosis and an explanation of its implications. It seemed that the crisis period obscured the professionals' ability to regard the events as a process and to attend to the family's needs for the future. It could be argued that these needs could have

been met when the immediate crisis subsided, but this did not occur. At that time, some 15 years ago, there appeared to be no continuity of care, or co-ordinated multi disciplinary team that could have highlighted these needs and followed Mr P from his hospital stay back into the care of his family.

Mrs K also found out by default, but her circumstances were different. She describes her sixty year old mother as “schizophrenic”, and came to understand that she was mentally ill because she required regular hospital care during Mrs K’s childhood. “When she was 17 she was put into the asylum. She was considered to have a psychiatric illness. I don’t know how she got out of that place.” Children are often totally dependent on their parents for an adequate explanation of the illness. It is not clear to what extent children of different ages are aware of the illness having a name or that other people may view having psychiatric treatment as different from attending hospital for dialysis or treatment for a malignancy. Children with one well parent usually rely on that person to talk to them. Where the sick parent is isolated the child faces the burden of having to make sense of the parent’s behaviour alone.

Should other Professionals Offer Information?

In my professional role, I frequently found myself with a dilemma over what to tell carers and service users. No one in the multi disciplinary team, except a doctor, may offer a diagnosis, but nurses and social workers usually spend far more time with the family and are frequently asked to name the problem.

I approached this problem in my own practice uncomfortably. I had no training to ‘diagnose’, but consultants would ask me for an evaluation of a patient’s mental state. At times, it felt unethical not to offer some clarity when a user or family were clearly anxious, confused, and wanted to know more. I personally offered information in the form of a rough category ‘given the knowledge we have at the moment, and that I am not medically trained, you seem to have a psychotic illness, we need to ask your consultant, perhaps he isn’t sure yet’. This approach felt more honest than avoiding the question or playing verbal

games. Professionals often seemed able to discuss the diagnosis between themselves, but saw no priority in sharing this with either the patient or the family.

If a psychiatrist was involved with the case it was easy to suggest that the user or carer approach them for more information. If no one was involved or if the carer felt that they wanted information but their relative did not, the doctor would reject the request because of the breaking of confidentiality.

Ethical problems arose even during the research, where families who were outside of the system wanted to have a name for their relative's behaviour, feelings, and thoughts.

Sharing the Diagnosis with Carers

Contemporary literature endorses the need to share the diagnosis with informal carers and with the user. Atkinson notes that reasons for sharing the diagnosis are threefold: 'moral', 'clinical' and 'practical' (1989:22). She stresses the positive aspects of diagnosis which can be a helpful clinical tool in dealing with issues of guilt and blame. Patients and families can be encouraged to deal with feelings of blame around the illness, within the context of giving a diagnosis. Dealing with a patient's or family's search after meaning can only begin to be dealt with once the diagnosis has been divulged (Atkinson, 1989:23).

Atkinson adds that people with schizophrenia can often discover diagnosis by accident; one man was told by a job centre clerk. She also suggests that people affected by the illness need a banner behind which they can gather to share their problems and fight for their rights (1989:23-24).

It has been argued that when researchers discuss mental illness they focus on schizophrenia to the exclusion of other problems. There is certainly a larger body of literature about schizophrenia and families. Discussion about

diagnosis and confidentiality tending to feature schizophrenia, perhaps because it is felt to be a particularly stigmatising disorder. Certainly schizophrenia can have far reaching consequences for all the user's family. This makes the debate over confidentiality and the availability of diagnoses to carers more compelling than, say, a diagnosis of obsessive compulsive disorder. Examples of literature that focus on schizophrenia include Carstairs et al, 1978; Atkinson, 1989; Kuipers et al, 1992 and Atkinson and Coia, 1995. Some research papers have adopted theoretical approaches (for example the expressed emotion model) and profitability adapted them to other diagnostic groups. In the current study the practice applied to people considered to suffer schizophrenia was also applied to people said to 'have' manic depression. The same issues of the carer's rights and patient confidentiality arose. There were around twice the number of people in the current study diagnosed as having schizophrenia than bipolar disorder (this reflecting the difference in incidence in the larger population). Both groups were commonly offered a transitional label of depression which might pass through subsequent stages of modification.

An Example of Good Practice in the Provision of Diagnosis

In formulating a model for the provision of diagnosis, I am drawn to the positive experience of my partner. It is not clear whether the task was carried out in such a positive way because of our perceived intellectual background, or because I was an Approved Social Worker. At any rate, the principles could be applied to working with people from any background and simply imply a commitment to partnership.

I have related how we sought advice from the GP. At that time a diagnosis *was not* required, as our common sense and prior experience suggested that my partner was depressed. This was confirmed by the choice of medication, an anti depressant. Prior attempts over the past 12 years had been rather fruitless in my partner's eyes and he had received a query diagnosis of 'psychotic depression'. The move to obtain a clearer diagnosis came through discussion

with the CPN. There were additional features of the illness and these were continuing to trouble us. Relatives of people with severe mental illness may describe “strange symptoms”, things that go beyond what they consider to be the bounds of normal experience and of depression. My partner saw pictures in things. We could tell that he was not hallucinating, but he was surrounded by goblins, skulls and hideous creatures who inhabited any patterned wallpaper, carpet, material, etc. He could not close his eyes to escape as the ‘demons’ were waiting on the inside too.

We had rather more information to go on than many people. We discussed the symptoms at length and tried to compare them to other things we knew. We looked at the worst case scenario, which for us was represented by a diagnosis of schizophrenia, and discussed what it would mean in terms of prognosis and medication. We talked about the associated stigma and who could be told what.

We finally saw the consultant in December 1993. We had waited three weeks, but it had felt like an eternity. The diagnostic interview was the most rigorous I had ever seen. With my partner’s agreement I was present. Evidence was collected for each sign and symptom. It was not considered present unless we all agreed. A spirit of collaboration was created and as my partner had taken part in each phase of the decision making he owned the outcome. The discussion lasted four hours. We were told he had a form of obsessive compulsive disorder and associated depression. OCD can cause people to experience unpleasant intrusive thoughts or images. In his case it was thoughts and images about suicide, especially hanging. The medication was negotiated patiently with him and case notes (normally only sent to the GP), followed in the post. The process was open and empowering. It was also conducted within a framework created through the use of excellent communication skills.

This was only the first stage in uncovering the diagnosis (there are three), but at that point, the specialist's knowledge was shared fully and sensitively. It represented the consultant's honest opinion at that time.

Sharing the Diagnosis with the Carer, but who is the Carer?

In my partner's case, the patient and consultant were comfortable about involving me as the carer. My position was clear, as next of kin, nearest relative under the Mental Health Act 1983, and as the person providing day-to-day emotional support and physical care. This position is often not so straightforward. There may be several siblings, none of whom lives with the user, or a parent, partner, and adult child all under the same roof. Given these circumstances, with whom do professionals share the diagnosis? It may not be productive to ask the user who is the *main* carer, especially if they do not accept that they require support. In the same way, if people are loosely involved in caring, what level of information should be shared with them? Perhaps these issues can only be approached, through the consideration of individual cases, with the whole multi-disciplinary team. Cultural differences pertaining to the role of extended family members will also need consideration (Kuipers et al, 1992:84).

Telling Children

There is scant information available for young children of people with severe mental illness and it is only recently that they have become recognised as 'young carers' (Rickford, 1995 b:25-25). Older children can be given leaflets, such as the one supplied by the Manic Depressive Fellowship. Like adult members of the family, children struggle with trying to understand their parents' behaviour. If the parent is unwell episodically, the child can be helped to regard symptoms as illness (Kuipers et al, 1992:75). Where the child is with one parent alone and where the illness is chronic, they may know nothing else. I made the decision to provide my son with a diagnosis because I felt he had a moral right to an explanation. Though not a carer per se (he did not feed my partner or calm him down), he was, like me, 'a walker on egg shells'.

Constantly searching their own behaviour for fault and trying to anticipate the user's moods, egg shell walkers need an explanation, even if they are five years old. I am sure I waited too long before doing this but that some people would still condemn my actions. I explained to our son that his daddy suffered "poorly thoughts and feelings". Apparently, children do not have problems with the separation of body and mind. We acted out his Rabbit's consultation with the psychiatrist and took him to the hospital regularly. A colourfully illustrated book along the lines of 'Spot visits the psychiatrist' would have been very welcome.

Rickford (1995 b:25) notes that 'age appropriate information for children about mental illness is hard to come by, and specifically targeted support is still rare, despite children of mentally ill parents being a classic example of "children in need" under the Children Act 1989'.

Given the disruption, physical and emotional strain experienced by close family of all ages there can be little excuse for denying them adequate information. Diagnosis can relieve guilt and provide a framework for facing difficulties. However, the procedures used to divulge and interpret diagnoses, whether with the family, or with the user alone, appear to be ad hoc and ill considered. Examples where diagnosis has been offered sensitively, with consideration given to its emotional impact, to the language used, and with the involvement of significant family members are rare. User/survivor opinion has often tended to argue for the abandonment of 'labels', rather than for the sharing of accurate, detailed diagnostic information.

The appropriateness of illness related procedures in this whole area calls for re-evaluation. The issue of confidentiality becomes paradoxically abusive, threatening the well being of someone who cannot recognise the changes in themselves and also those who are closely involved with them. New models of practice and the re-definition of this area, possibly outside of contemporary medical and legal frameworks is needed.

Telling Other People

Diagnosis may prove valuable to users and carers in some respects but it also represents a public recognition of one's problems. Even at this stage many carers will choose to ignore and deny the implications. Who can blame them?

This section considers how people deal with the problem of sharing their relative's label with others. With one breath people will tell you that to suffer mental illness is to be *ill* and *ill* people cannot be held responsible for their sickness, but, as I have argued earlier, the illness model is inadequate and its application is tolerated but not completely adopted by many people. I frequently heard professionals voice such opinions. One nursing assistant told me "that all they (the patients) need is a dose of hard work. The patients are only in hospital because they are unable to cope with the pressures of holding down a job and home". Such attitudes may be challenged, but not eradicated by training. Increasing reliance on unqualified staff will mean these attitudes will persist.

The attitudes people hold towards the mentally ill are rooted in their recognition as deviants. Scull notes that people were cared for at home, by the local community, before the 18th century. He adds that the

amorphous class of the morally disreputable, the indigent and powerless - including such elements as vagrants, minor criminals, the insane and the physically handicapped - was managed in essentially similar ways. Characteristically, little effort was made to segregate such 'problem populations' into separate receptacles designed to keep them apart from the rest of society (Scull, 1985:18).

Scull challenges the perception that this system was destroyed by industrial change and the geographical mobility of family members alone. He argues that the bonds that linked prosperous people to the less fortunate were eroded by

the advent of capitalism (1985:22). People no longer felt an obligation to care for the vulnerable in their community, as paternalistic relationships were replaced by market ones.

Whether cared for at home or in an asylum, the insane can be seen as requiring significant support. They are unable (or unwilling?) to adequately fulfil an adult role as a parent, partner or bread winner. To make matters worse, the insane can be viewed as unpredictable and aggressive (Purves, 1993:15 and Henderson 1993:31). The recent stream of public enquiries has only confirmed this. In the street where my father grew up and close to where my parents now live, a man diagnosed with schizophrenia ran 'amok' with a gun, killing a young father. In the press his name was distorted to 'Satan'. Fear of mentally ill people is also prevalent amongst the police. Rickford (1995:18) noted that in the Clunis report police were described as sharing 'the general public's ignorance and fear of mental illness'. Prins' report on the deaths of black patients in Broadmoor Special Hospital noted that general fear and prejudice was also fuelled by racism amongst staff (1993:51). Each incident can be viewed as isolated, and each example of prejudice as anecdotal, but they reflect, I believe, an underlying picture and broadcast a specific message to users and their families.

Although 'the mentally ill' are often viewed as a unitary group (Atkinson & Coia, 1995:24), the terms schizophrenic and manic depressive are heard frequently in the media and have strong negative connotations. Maclean's study found that people feared the embarrassing behaviour of mentally ill people as well as their potential aggression (1995:24).

How do carers deal with this knowledge and what strategies do they adopt in sharing information? The desire to conceal also affects users. "There's a stigma about it, it's humiliating. On one level I want to broadcast to people, I've been ill, will you please accept me, on another level if I want a job..." (Souhami, 1989:22). Campbell also describes the all-pervading loss of control that characterises mental illness and draws attention to the threatening presence of

the option of compulsory treatment (Campbell, 1989:15). People receiving psychiatric care describe a disempowerment that makes itself felt throughout every aspect of their lives. One is not a patient only when acutely ill and in hospital, but also increasingly a 'community mental patient' (Barham & Hayward, 1991:38). The low status of the mentally ill is something of which they are acutely aware. It is confirmed by a lack of 'useful' activity (1991:39) in a society which equates occupation with worth.

I came to view the process as akin to being 'out' about one's sexuality. There seemed to be distinct parallels! One had a secret which separated one from others, it purveyed stigma and could lead to social isolation, rejection by friends and family, and blight career prospects. The situation was complicated by the fact that details of my partner's illness affected me but were not wholly mine to disclose. If I chose to confide in a friend, I was breaking confidence. Mr R used the term being "out" spontaneously. It had required some years of adjustment before he said he felt able to share the information with others. He discussed his daughter's diagnosis of schizophrenia openly in the school staff room, this was followed by an awkward silence. Mr R said "everybody stopped talking. You'd have thought that I'd said she was a mass murderer". He felt that people had not avoided his family because of the illness, but that they did find it difficult to talk about. He preferred "to be precise and to apply the most accurate label available, then you know what you are dealing with".

Reaching a stage of being 'out' may occur in a number of ways. For Mr R the disclosure was by choice. Having had time to accept the diagnosis, his daughter also accepting it, he made the decision to discuss the illness openly. From this point of view he was able to remain in control of the situation. Others may bowdlerise the nature of the illness or hide it completely, only to have their secret forcibly exposed during a crisis. As an ASW, I have witnessed many public 'extractions'. On one occasion, despite my efforts to keep the procedure as quiet as possible, people lined up to watch the police and ambulance men remove their sedated mentally ill neighbour by stretcher. If one's status as a

mentally ill person is exposed in this way it can have a devastating effect on the user and their family.

In my partner's case, the release of information was very calculated and I possessed a prior knowledge of the likely scenarios, trying to control the information released. Prior to hospital admission, he was able to indulge in 'passing' (Goffman, 1986). He was seen to have depression, he was just like everyone else, not a lunatic, and hence 'passed' as 'normal'. He never denied having suffered periods of depression and a short period in hospital, but this was not his defining characteristic. He worked part time and cared for our son. People in rural communities are very visible and it would have been impossible to pretend 'he had gone away on business', so when my partner was admitted the first time, we agreed a policy of 'openness', or at least partial openness. My notes were brief at that time, things felt painful and too hectic to be concerned with record keeping. I noted that

we agreed to be open and honest. Difficult in a rural community. Stigma is rife. People were shocked but OK (Personal Caring Diary, February, 1994).

I walked into the Coop and casually explained he was in hospital. "Was it bad?" "Yes, very!" "Did he go in himself or did they make him?" I bit my tongue and said, "No, he went in himself".

When people are admitted for physical illnesses there are socially prescribed responses, but Yarrow et al (1955:33) note these are absent in mental illness. Nevertheless people did visit and send cards. Some also began to discuss mental illness and self harm in their own families, of which I had been unaware.

Despite this policy of openness, we were selective in what we told people. I can observe a continuum through which our descriptions passed, from avoiding the topic to full exposure. The process was very calculated and we consciously

managed the information that was released. This desire for confidentiality was also thoroughly endorsed by colleagues at the hospital who began to consider how they might deal with a similar dilemma in their own lives.

carer denies illness 1.	carer recognises illness but conceals this from others 2.	carer describes problem to others as physical 3.	carer acknowledges that relative has a mild mental health problem 4.	carer may refer to illness as 'depression' 5.
carer acknowledges severity of mental health problem 6.	carer openly describes problem as schizophrenia or manic depression 7.			

At first, the physical aspects of the illness were emphasised. My partner did indeed have a thyroid problem. In time, we acknowledged the greater part played by depression. It was relatively easy to talk about depression. It conjured up the image of a sick unfortunate, but I omitted to add the additional details about manic behaviour. Yarrow et al (1955:34-35) noted that when members of the general population were asked if they would discuss mental illness in the family or themselves, with others, the majority said they would conceal the information. Amongst the wives in the Yarrow Study, about one third talked of their husband's admission minimally, another third concealed the matter carefully (1955:35). Yarrow et al noted that the wives were torn between wishing to conceal something they felt embarrassed at and needing to share their feelings. Some felt they had ended up admitting more than they had intended and felt vulnerable because of this (1955:37).

I felt a great sense of relief in being 'out'. The pressure to absorb, conceal, and the worry about what the future might hold, had been a nagging presence for

some years. It was much easier to be honest about where my partner was staying and that he was having psychiatric treatment. However, the story I gave never quite fitted the facts and gradually additional details were added. So initially the problem was described as being a purely physical illness, but gradually growing recognition was given to the importance of the mental health problem. The decision to reveal the full nature of the illness followed public displays of irritable mania where the depressive label no longer held.

On one occasion, when a friend's patience about my partner's illness was exhausted, my partner decided to reveal the true extent of his symptoms. He began to describe the irritability, suicidal thoughts and bizarre mental images. It did not provoke understanding, but evoked disgust. The friend has not called since.

People in this position are constantly threatened by the thought of an inappropriate, uncontrolled, public exposure of symptoms and that this might lead to the involvement of the police. Given this knowledge, concealing information will always remain a gamble. People of lower social status and black people, who are statistically more at risk from compulsory intervention in the course of their mental health problems, remain particularly vulnerable to having the painful aspects of their illness exposed without their control.

Having a close family member suffer from severe mental illness is something that people find difficult to share. The stigma did not affect relatives of people with dementia, as it appears that dementia has become accepted as a tragic physical illness, in a way that schizophrenia and bipolar disorder have not. Those whose relatives had symptoms but no diagnostic label, and who denied having a mental health problem experienced particular difficulties. It was almost impossible for such carers to discuss the symptoms with others because their nature was disturbing and they lacked the protection that even an inadequate psychiatric diagnosis could offer. How can you expect support

when all you seem to be describing is your relative's laziness, irritability and general failure to cope with life?

Goffman's work on stigma, and the concept of a spoilt identity was entirely applicable in these situations. Carers of people with severe mental illness were engaged in an attempt to project an image of normality, but the illness could not always be subjugated. It would leak out or at times even, flood every aspect of the user's self making the preservation of an acceptable identity tenuous at best.

Chapter six

Experiencing the System

Those First Few Weeks

Many carers could remember little about the early phase of their relative's illness, or of the time when, in sociological terms, the illness became a social fact (Clausen et al, 1955a) and their relative had to be admitted to hospital. Some people found it hard to remember ,eg in Mrs Q's case, as it was over twenty years ago. In addition, some carers had not been central figures in providing support at that time. Mrs L and Mrs B were deeply affected by their sisters' illnesses, but the care fell on their sisters' husbands. Mrs L and Mrs B offered what support they could, usually by taking the children. Even amongst those whose relatives had been ill only one or two years, memories faded quickly. I noted this 'amnesia' in myself as well as in study subjects, and I began to suspect that it might act as a protection. Gradually, during the discussion, carers would begin to recall incidents that they had forgotten, often in an erratic, piecemeal way.

The Build Up

Many relatives were not admitted after the first 'crisis', but after an exacerbation of problems that made care in hospital a necessity. This invariably meant that families had witnessed painful changes in their loved one, and had experienced things they might prefer to forget. Talking to carers can be deceptive, for at times they could look composed, but although the surface may have healed over the pain is left deep inside and as we talked feelings would re-emerge. As one mother said she felt she was "bleeding inside".

Accessing the Memories

Despite having a 'caring-research diary', and the transcripts of interviews, it remains difficult to reach my memories and those of the study subjects. In order to capture the flavour of the experiences, a research colleague interviewed me soon after my partner's first admission. Although this was at my request, she commented that I seemed 'strange' and that her attempt to convey my 'pain' in the transcripts felt wholly inadequate. When people ask what had happened, one tends to relate the events and ignore the emotions. There are global terms that can be used to convey the mental and physical distress associated with a major event, such as a bereavement, but these are absent in this area, and the carer may find it almost impossible to convey what they are experiencing. Some of my language is emotional but I believe this is entirely appropriate.

Experiences Prior to Admission

Carers seemed to have had to reach deep inside to recall their experiences during the research interviews. Some carers told me of symptoms in their relative of which I had been unaware (even though I had been their worker). Once past, these problems were best forgotten and it was unfair to draw the patient's attention to them. Mr and Mrs D's daughter became "aggressive, she pulled things off the walls. She began to wet herself". Mrs A's daughter would "stay up all night long and could not be left alone as she set fire to things". Mrs E's son "lay on the floor and asked for a Bible as he felt he was dying". Far from being weak and frail, relatives became energetic and erratic. They could not be left alone for fear of what they might do. They would fail to wash, change their clothes, or deal with their menstrual periods, but at the same time did not recognise they needed any assistance. It is hard enough waiting on someone who will adopt the patient role and accept being attended to, but almost impossible when they resent what is perceived as interference. Carers at this stage desperately wanted to 'keep them at home' and the recognition that an admission to hospital was becoming unavoidable was seen as a defeat.

Feelings of guilt at not being able to manage at home were often compounded by the comments of the relative. At this stage the relative might have periods where they recognised that they were increasingly losing control and would plead not to be sent to hospital.

For all the families, those supporting people with dementia as well as a severe mental illness of a non-organic type, the first admission held great symbolic significance. For the families of people with dementia the decision to allow their relative to be cared for in an institutional setting marked the break with a former pattern of life. The decision to seek admission tended to be a long term one, for people had reached a point where they could no longer cope. This might be after a period of gradual deterioration in their relative, but accepting the need to act was often brought about by some crisis. The crisis could be an accident with the cooker, or fire, a decline in the carer's own health, or more rarely an aggressive outburst by the relative.

Accepting the need for admission either to hospital or some form of residential care was viewed as a mark of failure by several of the supporters of older people with dementia. Indeed, one of the most positive aspects of the caring experience appeared to be when a carer had succeeded in providing care in their own home. Such carers talked with great pride about the degree of attention they were able to offer. One woman had been denied the opportunity to care for her brother in her home and this was a profound source of disappointment to her. In this woman's opinion, residential or nursing care was incapable of matching the quality of care that could be given by one's own family, and other carers endorsed this attitude.

Carers of people with severe mental illness also feel saddened at what can feel like abandoning their loved one to the hospital. There are significant differences however, in that it is very likely that the first admission is the beginning of a cycle. Rather than having one's relative admitted and accepting that one can not manage, the patients are often quickly discharged back to the

carer. For people in the current study the relief of recovery was often followed by another slide towards relapse. This meant facing the painful fact that the family could not manage over and over again.

Things usually became very difficult before families would accept or seek admission. During the weeks prior to my partner's first admission his symptoms became intensified. He was increasingly depressed and retarded. Williams (1992:4-5) notes that psychomotor retardation is one of the core changes used to diagnose an episode of major depression). I would come in from work and he would have hardly moved from the chair all day. The essential tasks were performed (just), the dogs were exercised and our son collected from school, but he stopped writing, reading, and painting. Although it was bitterly cold, he could not be bothered to light a fire. Despite taking a huge dose of antidepressant, three times the recommended dose, he remained physically frozen and "thought of death each day". The other aspects of the illness were harder to discuss. He knew he was depressed, but did not recognise his 'mania'.

I came home from work ready to accompany him to his play. It was the first night - he had to go, he was starring in two scenes and had written the third. My parents had come to baby-sit and watched the whole episode. He said I was shouting at our son, so although I did not think I was, I checked my voice and went into the front room. He began to go bright red and screamed that he wanted to strangle me. I kept protesting my innocence, what had I done? He ran up the stairs to the attic. I could not say much to my mother, except that I thought he had gone 'mad'. When I followed him up, he had been banging his head and was crouched on the floor. I began to cry. He shouted "help me, help me". Then I knew he was ill, it was not temper, or bad behaviour, he was desperately ill. We did not

call the doctor, as we knew he would have been sectioned, we got up and went to the play (Personal Caring Diary, February 1993).

These episodes of, I did not know what, occurred at increasingly regular intervals. I went to work shaking, our son 'wrote' to the GP "please help my dad". Eventually, he went into hospital, not only to cure his depression, but in order to protect his family. Of course I could tell people he was depressed, but not that he was crazy. People have a stereotype of madness. He would often ask if he would lose his sanity and never regain it. My partner had the disturbing ability to fluctuate from lucidity to madness and back in less than an hour. I thought seriously of leaving home, but could still see the person trapped inside, desperately frightened and needing help. Other relatives endorse this view, however frightening they become 'one can still see the little boy inside'.

Many of the families in the study now became familiar with the threat of self harm and this presented another ugly aspect of the problem. The illness was life threatening, yet lacked any tangible form. One could not relax one's fight against it because of the risk that it would finally win. Carers talked of the overdoses, of walking their relatives up and down before the ambulance came and of the fear of 'finding them'. I will discuss this aspect more fully in a later chapter but it became influential in forcing families to accept a hospital admission.

An aspect of severe mental illness that appears largely unacknowledged in the academic literature is the illness as a *being*. My partner's illness seemed to have a life of its own. He described it as the "dark parasite" or the "succubus". I felt it was like "the angel of death" and each time I fought through a crisis and prevented him from being snatched away, it let me know it would be back to try again. This theme has been present in autobiographical literature and fiction however its recognition by professionals might aid their ability to empathise with users.

The First Admission

Information about admission to hospital suggests that relatives, especially spouses, can suffer extreme distress when their partners are admitted for physical treatment. Their suffering 'both starts and remains at a higher level than for other carers' (Parker, 1994:122).

The focus of concern, at least in medical spheres, is around the patient, and moves from the community into the hospital. The popular view is that the carer can have a rest. This is rather optimistic and may not be possible until the carer and relative are much more experienced in their psychiatric careers. The first admission was often relatively long, months rather than weeks.

Inmates

In contrast to being admitted for physical problems, being admitted for a psychiatric problem is a sobering experience. "You feel like nothing, there is an acute lack of status, you are a mental patient." Caring relatives also have to get used to the idea that their loved one is a mental patient and this knowledge in itself was enough to make many mothers cry. The sight of the other patients can also come as a shock. We overcame this with a string of jokes about dropping cigarette ends and of being killed in the rush to pick them up. Goffman used the term 'inmate' (1986b:23) to refer to mental inpatients and though not versed in sociology, my partner adopted the expression spontaneously. Many people did indeed look like 'inmates', through the effects of mental suffering, medication, and poverty. As a middle class punter, my partner was able to afford luxuries; CDs, trips to the chip shop, and new clothes. Attending to his clothes became a symbolic duty for me and represented my attempt to prevent him from sinking into institutionalisation.

The Redundant Carer

Prior to admission to hospital the carer may feel they have been wholly responsible for their relative's welfare. After the chaos and draining activity of the previous weeks, the house may feel silent and empty. The carer becomes a visitor to the ward, no longer routinely advised of the treatment plan, or able to discuss how their relative is responding. This de facto secrecy on the part of staff appears to extend to non-psychiatric treatments. A colleague, whose husband was admitted for tests, was not provided with any information other than what she overheard when the staff handover was conducted next to her partner's bed.

Visiting a relative in a mental hospital appeared to have more significance to families than 'merely' taking chocolates or a card to someone recovering from an operation. Despite the disfiguring impact of much physical illness, for example surgery and chemo therapy given for cancer, the presence of a major psychiatric illness appeared to challenge the user's status as a person. Their relative is surrounded by other users who may have entered and remained within the system, and those people are effective reminders about what can happen to your own loved one. As one mother explained, "I saw him queuing up for his tablets with the others and I thought, no my son doesn't belong with *them*." This concern to protect the person's dignity as a real human being (because *schizophrenics* are not afforded that right) extended to the carers of people with dementia. A spouse carer was particularly upset by the staff losing his wife's dresses and dressing her in communal ward clothes. "She was always so smart". It goes without saying that the communal clothes were dreadful, cheerless and unflattering. This act represented the staff's inability to regard his wife as an individual with her own taste.

Anxiety

Many carers referred to the first admission, and to the time when they “could not eat or sleep”. I did not sleep more than two hours a night for the first week. I got up each day feeling drained and went to work, but could not concentrate. I felt little confidence in the hospital system and wondered what they would ‘do to him’. Our situation was probably highlighted by my fear of ECT. Electroconvulsive therapy as a treatment causes a great deal of lay fear (‘One Flew Over the Cuckoo’s Nest’) and this is regularly expressed in user/survivor articles (see Taylor’s account of forced ECT, 1995). My own fear was not helped by colleagues’ use of phrases like ‘frying brains’. I had every fear that my partner might leave hospital a vegetable and colleagues did not feel able to reassure me.

The Visits

Life for the carer while their relative is in hospital is also physically stressful. There are the daily visits and in the case of rural families, this may involve long journeys. There is the washing to do, children to care for, and bills to see to. The visits themselves are not easy. Mrs U’s son thought he was the “elephant man”. Other relatives were angry at the admission and blamed their carer for betraying them. There were the ‘phone calls’ with some relatives phoning ten times a day asking to come home or demanding cigarettes. At the times when my partner was most ill, he would phone up and insist that he should come home. I would usually feel I had to drive to the hospital and persuade him to stay. The most traumatic aspect of visiting was going to see someone who was not themselves. Carers recall the angry, cruel comments that their relatives made at these times. Mrs O’s son once told her that he would “dance on her grave and piss on her ashes”. If one could view this as the illness one could cope, but carers often felt uncertain and wondered if they were deluding themselves, and that their relative was really aggressive and sarcastic. At other times visits could be emotionally sustaining, but it was wholly unpredictable and one never knew what to expect or exactly ‘who’ one was going to see.

“More than the Brain Can Take”

I am convinced that however hard I try to convey the quality of these experiences, the words will be inadequate. The carers I interviewed were not in crisis, and I was unprepared to prey on families whose suffering was more immediate. The conversations were honest and described events. The accompanying emotions were far more difficult to pin down accurately. Towards the end of the discussion subjects often added that they had failed to convey how they had felt and added “it was awful”, “it tears you apart”, “it is more than the brain can take”. Without wishing to exaggerate, subjects agreed that the experience was appalling.

Emotional Pain

There is an overwhelming emotional pain. Perhaps this is the result of the close bond being disrupted by painful changes in the relative. Carers described their relative as “having evil eyes”, and I had noticed how my partner’s face would twist in a sinister and frightening way. It became easy for carers to assess how relatives were by their facial expression. As Bowlby states in his work on attachment and loss, that the “loss of a loved person is one of the most intensively painful experiences any human being can suffer” (Bowlby, 1986:7).

It would be insensitive to try to create a ‘hierarchy of losses’, but I feel confident in claiming that the effect of severe mental illness is to cause a major violation in the bond between the carer and their relative. The pain results from the way in which the relative’s human qualities are distorted. In many respects the changes in the person’s self can prove more disturbing than the impact of illness on the body. At least the latter is afforded external recognition by society.

The suspiciousness and anger that relatives so frequently direct at close family is particularly painful. Mrs CC’s husband believes she is unfaithful, other sufferers feel plotted against, betrayed, poisoned, and rejected. Similar

problems may occur in the early phases of Alzheimer's disease. In his account of caring for his wife's friend, Heywood remembers how Maria became suspicious and angry towards him. At first, she accused him of being "evil" and having "made her sick". Yet the next day, she was quite 'sane' again. Such accusations followed by normal behaviour were to become a constant pattern (Heywood, 1994:3).

There is the hurt of being verbally abused and rejected, but also the sadness of knowing that the relative really does believe that everyone has let them down. This leaves carers feeling helpless and empathising with their relative's feelings of despair and isolation. No amount of arguing, pleading, or rational provision of evidence will affect the relative's views at such times.

Some relatives pour all their anger at one person rather than at another. Mrs V's daughter channels her paranoia at her mother, causing tension in the family, as Mr V was unable to appreciate the effect this is having. "I've had a hell of a life with her. I've been kicked, been called every dirty name you can imagine and had boiling tea thrown over me." In Mrs V's case, it began when her daughter began to accuse her of taking her grandma's curtains. Mrs V was totally confused by her daughter's attitude at the time, but these sort of outbursts became all too familiar. Some families are spared these problems, and throughout the illness their relative maintains confidence in them, but a marked deterioration in the relationship is much more frequent. Mrs L says that when her sister becomes ill, their relationship is the first casualty, "I am like a rag to a bull. Afterwards she will apologise to strangers, but not to me". Children are not exempt from this and in some cases were also targets of paranoia.

Given the frequency with which close relationships suffer, there is a role for professionals to reassure carers and interpret this as part of the illness. Such advice could prevent a great deal of suffering. In the first weeks when I was unable to reconcile how my partner felt about me, ward staff confidently told me

that he was always worse when I was there. At times this drove me to despair. I needed to be near him, but could not cope when I was there.

I feel like my heart is broken. I feel suicidal. I am the barometer for his illness. It is always me. I am the one who provokes his anger. So when he thumps the wall and screams "bitch", I never know if it is me to blame or the illness. I can say it's the illness, but if I let them see I am upset, they will not let him go home and he will call me a traitor. Then he told me afterwards, when we made it up, after we had pulled each other to bits and I had cried in front of the nurses, that he had felt angry all day, but had not told anyone in case they would not give him leave (Personal Caring Diary, March 1993).

Close relationships are also an early casualty in depression and work by Weissman and Paykel notes a deterioration in the relationship between women patients and their partners and children (1974). Given this knowledge, it is important for carers to be given support and reassurance that it is the illness, not their relative that is behaving cruelly.

Expressing love, affection, and offering care is the essence of a close relationship, but the 'carer' is denied the opportunity to do these things. The sicker the relative becomes, the more likely they are to pull away from loved ones and to resist attempts to show support and affection. In some cases the relative will leave the relationship and caring environment altogether. In severe mental illness caring is often epitomised by a paradoxical inability to care for someone who may be dirty, smelly, undernourished, living in poor conditions and alienating everyone around them. Anne Devenson (1992:256) describes her son's condition prior to his suicide (he was dirty, malnourished and had sores on his feet). Mrs X's son disappeared and was seen on television at a soup kitchen over Christmas. Mrs CC occasionally received descriptions from

friends of the change in her husband's behaviour and the deterioration in his appearance.

Fighting the Illness

Despite the sadness carers also describe with pride their commitment to fighting the illness. "You get this lioness instinct." Other family or friends who do not appear to be up to the fight often become resented as the carer feels they have no choice but to fight on alone, because the sufferer often cannot. Descriptions of other illnesses and their effects on the family also identify *fighting*. In describing husbands whose wives were having chemotherapy, Wilson recognises stages of "resolving to take on the fight" (1991:250). Mrs U decided that she had to use all her strength to fight for her son. Carers recognised that their determination might be all that prevented their relative's death.

Witnessing Suffering

Part of the carer's pain derives from seeing their relative suffer. Wilson's study is harrowing, she describes husbands' accounts of their wives' sickness after having treatment for cancer.

The pain of watching somebody that you love going through pain, going through agony, that is the hardest part. That was my hardest part - it was not the caring or the cleaning up, or helping her to the washroom or getting the pills (Wilson, 1991:259).

Terrible as cancer is, there is some sense in which mental health carers feel that cancer is normal and acceptable. The knowledge that someone has cancer will bring understanding from others, many who will have had contact with the illness themselves. Severe mental illness is invisible, cannot be detected by tests, and is associated with tremendous suffering, but this is accompanied with the suspicion that the pain may be self inflicted and symptomatic of weakness. The carer who is clearly distressed by their

relative's suffering may only fuel resentment against the sufferer who is now perceived as making their family suffer too. These feelings may lead the carer to try and hide how they feel, which only adds to their sense of isolation.

Mrs CC and I discussed a friend of mine severely injured in a car accident. She had come very close to death and had spent many months flat on her back. Mrs CC's immediate reaction was that this was terrible, but *normal*. If only her husband could have been ill in this way.

Over the coming weeks, the carer and the family will have their lives reshaped. Familiar routines, interests, social contacts, and hopes for the future will be jeopardised. These experiences can be overwhelming but as yet most families have not realised the implications for the future.

What it's like at the Hospital

Some people pass briefly through the system but the families in this study soon became part of it. This section will discuss carers' impressions of the *system*, ie the mental health system. For the majority of people with severe mental illness, and for their families, the early experiences were an introduction to a new way of life. Most patients have multiple admissions with periods of complete recovery or every intervening state to chronic ill health in between. New people quickly become aware of this. My partner began to notice "that you see the same people coming back again and again". Even for those whose relatives were well, and did not require hospital care, there is a need for monitoring of medication, help with employment, finances, etc. Relatives and their carers become part of a community within a community. Psychiatric activities come to structure all aspects of life for the user and their family.

Most people expect to have treatment for illness and to recover, but people with severe mental illnesses can face years of intervention in their lives. Like the treatment of diabetes, the cure can be rather inept and in some cases

complications arise. Monitoring is considered essential by professionals. It can be a depressing thought to realise what the future is likely to hold for you if you are twenty and have been diagnosed as having schizophrenia. No wonder some people decide to break 'free and to try to go it alone' without the professionals. Unfortunately, the person suffering a severe mental illness does not always have a choice, considered to present a danger to others, 'care' may be imposed through the Mental Health Act.

The study will attempt to review the system as experienced by the carer, but how users themselves experience care is also crucial for families. Always guilty, families want their relatives well cared for, respected and occupied. Carers are often acutely aware of the shortcomings of services, yet forced to try to persuade their relatives to accept them because there is nothing else.

Developments in Inpatient Care

It is important to recognise that some of the older carers' views of inpatient care have been influenced by the stigma associated with the old asylums. Conditions have undoubtedly improved, but attitudes are slow to change. Some adult children could recall having visited a parent in the asylum and are still bitter about such places and their relative's association with them. Other carers in the study supported young people who had experienced their first admission recently. Unless stated otherwise, carers' views of hospital inpatient care and of other support relate to services received within the last five years (since 1991).

The Hospital

Carers' initial impressions of the hospital occur at a time of acute emotional stress. As the initial horror subsides, or when their relative is readmitted, the carer is able to study the hospital at length. During the two years after his first admission, my partner had five further admissions. This can be considered fairly typical for an illness of such severity. Indeed, after having gone some eight months between admissions staff commented to him that "he had done well to stay out so long". He found this comment utterly daunting.

All the relatives in the study had *been in*, as it is known. When carers meet it is polite to enquire "is she in or out at the moment?". It is this experience of admission that seems to separate the mental health 'community' from others who may have had some mental health problems requiring tablets or a few weeks off work. After admission it becomes much harder to avoid one's psychiatric status. Time off work can be disguised as post viral fatigue or being run down, but a month in psychiatric hospital cannot. Repeated admissions resist any attempt to conceal one's career as a psychiatric patient. It's a bit like having a criminal record.

As carers begin to acclimatise to the shock some feel critical of the standard of inpatient care. Some ten years ago, in the early eighties, Mr and Mrs S' son was admitted initially to an adolescent unit. They were upset by the standard of the adult ward to which he was subsequently transferred. "There were all these mad people walking about. There was an iron bed with a mattress on it. The paint was flaking off the walls and the curtains were torn." The family did not feel able to leave their son, nor did he wish to stay, but they were unable to cope with him at home and had to allow him to be readmitted, which caused considerable guilt on their part. Wards are not pleasant places and rarely meet with the image of sanctuary expected for sick, vulnerable people. A recent account by a professor of psychiatry covers this point.

Acute wards are reminiscent (to those with long clinical memories) of observation wards, those disturbed and varied reception units to which acutely disordered individuals were taken for triage and then transferred to where the treatment was, but today's wards *are* the treatment. On the personal criterion of "would be prepared to have one of my relatives admitted to this ward", too many acute wards are simply unacceptable (Watson, 1994:531).

Drugged up to the Eyeballs

Several relatives had been inpatients in the south of the region. The carers felt that people often appeared sedated and that little happened except that they sat around being 'monitored'. "I don't blame anyone for not wanting to go in there. You see them sitting there, drugged up to the eyeballs. Nothing seems to happen except they get monitored. It is the most depressing place I have ever been in my life." One carer complained that he visited daily and sat with his wife for hours, but no one "even offered me a cup of tea."

Some carers feared for their relative's safety, especially when they might be sharing a ward with people who appeared aggressive and had been brought in by the police. The concern over women and vulnerable patients being harassed by other patients is now well documented (Nairne and Smith, 1984:107-108).

Monitoring or Active Support?

For myself the hospital became associated with a profound sadness. I trailed in to visit day after day dreading the smell of stale cigarettes on the stairs. It was hard to hand over his care. In dealing with all the crises I had adopted a position of actively nursing my partner, but in hospital no one seemed to talk to him and the patients were rarely well enough to talk to one another. Hospital was a receptacle for containing people. I wondered how on earth they could know how he was when they did not talk to him. In my opinion he must have desperately needed to talk at that time.

Information

There was a universal absence of quality information. Carers who had entrusted their relative to the professionals sought regular information on progress and on treatment plans. Greer and Wing's study emphasised the need for initial information (1980:61) and said that 'many complained that they had turned to doctors or social workers for information but had received none'. A problem when the Greer study was conducted in the 70s, this situation had not been rectified. Carers felt excluded and worried. A recent discussion with a carer of someone with a physical illness suggests that poor communication is not necessarily limited to psychiatry.

One woman spoke of the trauma of her daily visits to see her son (22). He looked "so mad" and she felt a desperate need to talk to staff. "No one from the hospital ever came over and said do you want to talk or have five minutes. I was so grateful for any crust of bread that was thrown in my direction. I have to say, it was usually the support workers, the auxiliaries, who came over and said, 'You should have seen him last night, this is a bad time of day, last night he played scrabble and made us all tea'. This was a present to us, I can't believe they didn't have time, there were rooms and facilities. All of this affected my son because if someone had helped me with my emotions, I would have known what to say to him, but there is this business that he is grown up, and it's nothing to do with you. We are a family".

Information did not appear to be an issue with the dementia carers. It seemed to be provided at an early stage with a comment to the effect that nothing more could be done. Information becomes more important when there is talk of treatment and hope of recovery.

The Role of Talking

Not only was 'being talked to' valued highly by carers, it is also felt to be a need by patients. Rosenhan et al (1981) faked auditory hallucinations in order to gain admission to a US hospital. One of their saddest observations was of the negligible role played by 'talking'. They noted that 'heavy reliance on psychotropic medication tacitly contributes to depersonalisation by convincing staff that treatment is being conducted and that further patient contact may not be necessary' (1981:31). In fact, the more prestigious the professional, the less direct patient contact they had. To talk about one's fears, inner pain, interests and aspirations is a basic human need. Denied adequate companionship and support, users may be left alone to wait until their treatment (tablets) takes effect. This may be several days, a few weeks, or an unrealised goal. This in effect reduces a potentially therapeutic environment to a dumping ground.

Talking and Carers

It is suggested that counselling has become a universal, lucrative panacea (Gordon, 1995:22). To argue that carers need to talk is not to suggest that they must all have 'professional' counselling, but if carers as consumers are to be permitted to define their own needs, talking to someone was felt to be very important. Services revolve around the patient, and where talking to patients, rather than 'monitoring' them, receives little commitment, it is unlikely that professionals on the wards will actively talk to carers. It has been observed that talking to patients and families is something professionals do for their own purpose, usually collecting information.

Boredom

Hospital can be noisy and demoralising, but it is usually very boring. My partner would constantly complain of the boredom and I continually felt guilty. The hospital workshops offered knitting, crafts and woodwork. There was pool

and table tennis and the ubiquitous television. Unfortunately, the workshops closed at 3.30 pm and this left nothing to do until bed time. My partner was lucky and could afford to escape to the pub and chip shop. Most patients spent their limited resources on cigarettes and could not afford to go out, their benefits having been reduced after six weeks. Hospital staff have a clear role in engaging patients in activities but observation and study data suggest that administrative work was often given priority.

Valued Customers

Carers frequently felt guilty at where their relative was staying and at the lack of meaningful activity for less ill patients. Patients complained of feeling like “dirt”, “like nothing”, and this was keenly felt by their carers. Although hospitals actively displayed the Patient’s Charter patients’ actual status was still felt more akin to prison inmates than to valued clients. This point is made by Barker and Peck who argue that ‘survivors of the mental health system are no more consumers of mental health services than cockroaches are consumers of Rentokil’ (Braye and Preston-Shoot, 1995:28). These feelings are probably a legacy from the days of lunatic asylums and derived from the compulsory status of many of the patients even though most severely mentally ill people in hospital are informal they are acutely aware of the threat of detention under the Mental Health Act.

Seclusion

Another feature of inpatient care that confirmed the patients’ low status was the use of seclusion. Some of the patients who had been very disturbed were put in the seclusion room, a cell type room with a mattress on the floor. At another hospital a whole separate ward was used to contain acutely disturbed people. Visiting the locked ward or having a relative put in seclusion was a desperate experience for carers. Mrs N explained how afraid her 20 year old son had been. He had clung to her all night prior to admission. Once in hospital he was ‘sectioned’, ie detained under the Mental Health Act, and “dragged” from

her to a seclusion room. She could only think of how frightened he must have been, he had always been “gentle and quiet”.

The Case Presentation

Soon after my partner’s admission we were told that he was to be the subject of a case presentation. This is a process where a doctor will discuss an interesting case (person!) with colleagues. It provides the opportunity for junior doctors to hear of the symptoms, consider differential diagnoses and treatment. It also involves bringing in the patient. Wishing to co-operate fully my partner consented to this process and we sat outside the room waiting to go in. I insisted on accompanying him as I felt he was vulnerable and unsupported.

I put my head down and said hello (I knew 2/3 of the doctors in the room). Our consultant was away and another one asked my partner a series of diagnostic questions. My partner rabbitted on, he showed no embarrassment, and talked about his attempts to kill himself. There was no skill or sensitivity in the interviewer. Nothing to soften my pain. I sat and writhed. No one said “I know this is difficult, thank you for sharing it”. That would have made it bearable. They asked a few technical questions and I talked on an intellectual level. My partner carried on happily chatting. I turned to the audience and told them that the process was “ethically distasteful” and the embarrassed psychiatrist quickly wound the meeting up. I left the room and began to scream at a junior doctor. I went on and on, as all the pain and humiliation of many terrible months came out. I felt like I had been ‘raped in a court room’. My partner was fine, he was jacked up with ECT and hypomanic and they had taken advantage of him (Personal Caring Diary, March 1993).

Rather than complain, I met the senior psychiatrist to try to address the problems rationally and constructively. Unfortunately 'freak shows' are required by the Royal College of Psychiatrists in the training of junior doctors. As a social worker, the lack of dignity afforded to the patient, the emotional pressure, the ambivalent status of the patient's consent and failure to routinely offer a supporter to the patient make such presentations unpalatable.

Leave

Treatment follows a predictable course and early rehabilitation is sought by sending the patient on leave. Initially for a day, then a weekend, later a week or weeks prior to a discharge meeting. My own experience has been largely good. During my partner's admission (August 1995) the consultant checked with me that I felt my partner could be managed at home prior to discussing leave with him. Others, however, complained that there was no attempt to consider the carer's ability to support the patient. Carers were asked to accept their relative on leave while the patient was present. This made it difficult to say no or led to the relative feeling rejected. "She would ring up and say the doctor says I can come home if you will let me. Well I couldn't say that I didn't think she was well enough yet".

Mr C felt "staff were manipulative about leave. Patients shouldn't be allowed to just go and phone their family up to request leave because this puts the family in a difficult position. It would be far better if the ward phoned to check things out first". He said that his wife had been sent on leave when "she was vomiting and hardly fit to stand". Mr C had two children at home to care for in addition to his very sick wife. Mrs M added "they just sent him home and I was expected to cope".

Hospitals are clearly under pressure and it will become increasingly tempting to send patients on leave in order to maximise bed space. Given that carers are the focal agents of community care it would appear sensible and considerate to discuss any plans for leave with them first, but if a non-detainable patient insists on leaving the hospital one cannot keep them against their will. There

were however many examples given by carers where *they* felt that their relative ought to have been made to stay in hospital, if necessary under a section.

Having cared for her son on leave some years ago Mrs Q found he never wanted to go back. At that time (20 years ago) her son said he was put in freezing cold baths. She feels very guilty because she only recently learnt that this was true.

Carers wanted their relatives at home but patients could need intensive support during leave. It was also difficult to obtain money to help with expenses if the patient's benefit had been reduced. Such money for leave had to be claimed retrospectively. There was a remote chance of being given money towards food at a later date. Carers often had to supply money for cigarettes out of their own pockets. Many carers could not afford this expense but the Department of Social Security were frequently very unhelpful in such cases.

Not only did relatives not want to return after leave, some proved very difficult to convey back to hospital. Mrs P's son is in his 30's but when first ill he would shriek in the street and climb up lamp posts as his parents tried to walk him back to the hospital. This obviously provoked a response from passers-by. If their relative refused to return and was on a section, carers had the unpleasant task of reminding patients that the police would come to retrieve them if they did not return. This did little to alleviate the fears of relatives who suffered paranoia.

From a professional viewpoint, it is impossible for consultants to always gauge how well a patient is. Even if leave has been carefully arranged with the carer, accidents do occur and may lead to bitterness on the carer's behalf. Some carers felt that it should have been possible to assess the patient's mental state more accurately and to have kept the patient under hospital supervision. Having been offered weekend leave, Mrs B's sister a woman in her 60s, was

getting changed ready to go back to hospital. While her sister was downstairs she threw herself out of the window. This lady died in her sister's arms.

Another related problem was that of patients going absent without leave. This was only of concern to the hospital if the relative had been sectioned, otherwise patients could be deemed to have discharged themselves. Carers were often very worried if they learned that their relative was AWOL or had gone missing. One man walked many miles to try to get back to his family and it was this kind of experience that led to them deciding to care for him at home, despite his severe illness. Another man went AWOL and threw himself off a bridge sustaining severe injuries. Carers could not equate the fact that people needed to be legally detained, but nevertheless seemed to be able to walk out and harm themselves. They felt this suggested negligence. It was difficult as a professional to explain that very few people were locked in, or supervised on a one-to-one basis. However a higher ratio of nursing staff may have made sensitive but effective supervision more feasible.

Discharge

Some carers complained that their relatives were discharged without the carer's knowledge. The patient would simply turn up. Mrs M's brother was advised to live in a hostel two hundred miles away from his family in order to develop independence. Unfortunately he deteriorated and was admitted to the local hospital. They discharged him after a week and gave him the train fare home. Unfortunately he jumped off the intercity train causing permanent damage to his arm. This example of appalling practice occurred some 15 years ago.

Mrs N's son was first admitted only 3-4 years ago but was discharged without information or any follow-up. He had his medication reduced and soon relapsed, the diagnosis being schizophrenia. She appreciated the fact that they did not want to label him as schizophrenic but felt that whatever the problem was the family needed information and support after discharge. If he

had subsequently recovered, the family felt that they would have appreciated the consultant's honesty at the same time. One might argue that if the stigma was not so powerful it would be far easier for information to be given both to the user and any carer.

The Care Programme Approach introduced in 1991 (Gomersall et al, 1990) provides a system of comprehensive monitoring for all those with significant mental health needs, whether admitted to hospital or living in the community. Regular meetings held before discharge and throughout the treatment should be multi-disciplinary, involving the CPN, ward staff, consultant, social worker, and carer or a friend. It was difficult from the data obtained to form a picture that suggested that carers were *actively* involved in this process rather than merely present. One man cited "power" as a reason for the difficulty in taking on an active role. He found the meetings "intimidating". There was no apparent difference between articulate prosperous carers to those from poorer families in this respect. Even people from professional, caring backgrounds said they felt intimidated by the proceedings.

I was always involved in the care planning. I turned up at ward meetings, supported by our social worker, and she kept me informed about treatment plans. I suspected that my frequent presence must have been irritating at times, but with my partner's agreement I made a point of attending meetings and arguing our case if I felt this necessary. Although I was an articulate and experienced Approved Social Worker I found the process difficult. As a professional, attending meetings was a familiar activity and often involved a journey out in the car and coffee with colleagues. It was very different sitting for long periods on ward round all day waiting to be called in. It made all the patients anxious as they were consciously trying to control themselves in order to impress the doctor. Having one's personal life discussed felt invasive.

Time was another factor- attending meetings was and continues to be very time-consuming. I had to 'disappear' from work. On one occasion the staff were

slightly displeased that I was getting impatient but I had been bleeped to urgently assess a patient in the community. No thought is given to carers' work or child-care arrangements in such cases and one depends upon the (finite) goodwill of neighbours and one's employer.

In 1974 the situation was clearly expressed in the Greer and Wing survey of carers belonging to the National Schizophrenia Fellowship.

In general the main feeling about hospital care was that relatives were not included in the treatment plan and that their co-operation was not sought in spite of the fact that as soon as the patient left hospital they had to take responsibility. (Greer and Wing 1980:62)

Although the CPA arrangements should now be firmly in place it will take a change in culture to facilitate the active involvement of carers and of their relatives. The meetings reflect professional tradition rather than the needs of users and their families. (See 'policy' chapter for a discussion of care programme approach and the involvement of carers).

Being a Regular

Hospital for many families seems a familiar place. Given that it features so prominently in our lives, it does not seem unreasonable to ask that high standards be sought. There was evidence that as relatives' care progressed carers became much more au fait with the system. One mother "desperate to talk" about her son has developed an agreement with the ward that *she* can phone or call in for support for herself. She finds this very helpful indeed. Such arrangements are ad hoc, however, and take time to develop. (If at all).

During an admission of my partner in August 1995 I felt none of the dread of the hospital that I had once felt. I knew where the tea mugs were kept and which loos were likely to be clean. Our son liked the pool table and the canteen. I had come to terms with the fact that hospital was, and probably

would be, a part of our lives for the foreseeable future. We had spent the winter there, hot summer days, a wedding anniversary and a New Year but my partner always cries before he has to go in, partly at the realisation that he is a 'revolving door' patient.

This thesis includes the layers of experience as a carer and I have attempted to reflect changes in my perceptions. Reviewing the script only three weeks after writing it already feels ironic as current experience belies the complacency. The ability to cope with the system would seem to be tenuous.

Not all the carers in this study have adapted to and accepted their predicament. Much of one's attitude is dependent on how traumatic a relapse is, and on the speed of response to treatment. Some carers were so distressed by the nature of hospital care that they have never encouraged their relative to go back. This does not mean that their relative is mentally well- indeed, some people being cared for in the community were severely disturbed. Others 'wash their hands' and do not visit, phone, or offer any support. It is important to view this 'neglect' with compassion as it probably arises from emotional exhaustion.

No Beds

In order to be discharged one first must be admitted. With the closure of the old, large hospitals this is becoming increasingly problematic. Admissions to hospital cannot be used as an accurate index of relapse rates. In the past people were undoubtedly admitted more readily and for longer periods. The Greer and Wing survey of people with schizophrenia noted that:

In the 1930's before the introduction of any of the modern pharmacological treatments, the chance that someone with this diagnosis, who was admitted to a mental hospital for the first time, would be discharged within a period of two years, was only one in three. Once resident for as long as two years, the chance of ever being discharged at all became minimal. (Greer and Wing, 1974:2)

A whole army of nursing staff, auxiliaries, cleaners and porters made their living by servicing the large mental hospital in the study area. Indeed, it is the local industry, or was. The pressure to provide community care had led to a reduction in beds, and in-patient care is now viewed as a temporary phase in the care of people with severe mental illness. It is rightly reserved for periods of acute illness. The theory is admirable but there is strong evidence of increasing pressure on beds. Hollander and Slater gathered information about the availability of acute psychiatric beds in the North East Thames area in 1991. They received a number of responses indicating that people were being admitted to beds belonging to patients on leave, to camp beds in the ward office, and that there were delays in admitting patients who needed detention under the Mental Health Act (1994:532). Staff were engaged in making endless phone calls to secure beds, often sending patients to other hospitals. \Some patients who were felt to be suicidal or aggressive had absconded by the time a bed was found and a significant percentage (32%) could not be accommodated. (Holland and Slater 1994:532-3).

While there was little to suggest that a bed shortage was a local problem at the beginning of the current study (1991), this state of affairs changed as time elapsed. As people who would once have become long-stay patients spend their time between the 'community' and acute admission wards, and as the old hospital retracts, so the pressure on limited bed spaces in the acute units mounts.

In response to this pressure I made a formal complaint to the Community Health Council. Staff also noted that as a prospective patient deteriorated the opportunity for informal admission diminished. Before the situation became critical the patient might agree to admission but, in the absence of a bed, they would be allowed to deteriorate before being admitted compulsorily. Hollander and Slater argue that bed occupancy should ideally be at around 85%. It is efficient at this level. Should it be at 100% (which so many wards are),

hospitals will lose the ability to respond to crises (1994:553). Hollander and Slater note the frustration caused to professionals but the cost is actually borne by the person who is mentally ill in terms of suffering, isolation, and loss of control, and by caring families who must shoulder the provision of crisis care. Where carers can no longer cope there may be a permanent breakdown in the relationship. Isolated people may later require expensive community support or residential care, but this cost will be met by the Social Services budget for Community Care and not by the Health Service.

In the current study some local hospitals operate a waiting list. One must try to anticipate a relapse in order to be sure of obtaining a bed. In 1994 there were several crises involving disturbed behaviour where my partner was thought by a doctor, and by myself, to need admission, but the wards were fully occupied. The most bizarre consequence of this was when my partner was admitted on the grounds of gastrointestinal problems to a general medical bed. (The real reason for admission was risk of suicide) Staff on the medical ward were puzzled and unenthusiastic about his admission and my partner confused and guilty as "other people in the ward were dying".

I felt a sense of frustration and anger at being exploited as a carer. To nurse alone someone who is very sick, to care for a child, and to hold down a full-time job can feel impossible. Bed shortages are familiarly frequent. Even day-care facilities can be over subscribed. If crises are to be dealt with in the community, rapid response from community services should be made available and both health and social care needs addressed. At present my experience suggests that the process of assessment for social care is slow, and that given pressure on resources, services are more likely to be directed at people living alone, if at all. No one, in the current study, had received services during a crisis to enable them to cope for their relative in the community as an alternative to admission. Such services have been the subject of a demonstration project in one area of the study but were not generally available. They may possess public relations value rather than the possibility of widespread availability.

The physical burden of caring is well documented (for example Gilleard et al, 1984) and has been applied to a wide range of problems. Those who become disabled by the effects of arthritis, cancer, multiple sclerosis, and, more recently ME are unlikely to attend to the range of tasks that they once attempted. If they can cook, carry out paid work, clean, go shopping, and drive it is probable that they may require more frequent rests. However, life for mental health carers is rarely acknowledged to be hectic, both when the user is at home and when they are in hospital.

When an illness is 'mental' the balance between the emotional and physical aspects of caring will differ from those presenting with so-called physical illness. Carers of people with mental ill-health are less frequently engaged in personal care tasks (though they may be necessary) but are involved in taking over the management of the home and finances and providing intense emotional support and supervision. The draining effect of maintaining the home living environment is expressed succinctly by a wife care giver whose husband has dementia. She is quoted in Wright's study of couples where one partner suffers dementia. 'We never do anything - just work, eat, sleep, and go to church and life is spent. I miss not being normal (crying) (Wright, 1993:52).

Carers of people with dementia, interviewed in the current study, had not experienced difficulties around leave or in gaining admission to a hospital or residential unit. Once admitted it was generally accepted that their relative would remain there until their illness progressed. 'Leave' was more likely to consist of a regular day or days (at home if possible), but was not a prelude to discharge.

Carers of older people with dementia, however, are likely to find it increasingly difficult to gain admission to a free bed (ie Health Service Sector one) in the future, as the cost of paying for continuing care is gradually redefined as the responsibility of the local authority and of the patient themselves.

In the study area and in other regions there appears to be a shortage in the number of acute adult psychiatric beds currently purchased. The study indicates that the imminent closure of the long stay hospital, which is still being used to accommodate the overspill, will only intensify the situation. A failure to provide adequate inpatient care is a false economy. Strained beyond capacity, relationships will break down and people with mental health problems will be left isolated, rejected, and in need of costly community services. If quality services are provided when required, the patient's social network can remain intact to support them, preventing or reducing the admission.

People with mental health problems need access to a range of services from inpatient care to community support. All such services should offer a quality service and a rejection of the status of mental patients as recipients of charity.

Carers and Professionals

The Psychiatrists

As part of the system users and their families will meet a range of professionals and other workers or services designed to meet their needs. Contact with these may often be long term.

Literature about mental health users stresses the crucial role played by doctors in the lives of psychiatric patients (see Barham, 1991). By default doctors also come to play a major part in the lives of their carers. Virtually all the users in the current study had been referred to a psychiatrist. They usually continued to be in regular contact, even if the condition was felt to be stable. People with severe mental illness are almost always encouraged to take prophylactic medication, and this should be monitored by a specialist as there may be a risk of enduring side effects.

As I have noted, Goldberg and Huxley (1992) studied the pathways that people take to reach specialist mental health services. They note that GPs usually refer people with a severe illness (such as schizophrenia or bipolar disorder) to a psychiatrist. Occasionally people are seen by the psychiatrist directly (1992:52), most probably in an emergency. They observe that milder disorders tend to be dealt with by the GP: psychoses and severe depressions by the psychiatrist as out-patients or in hospital. It follows that if people in the current study have been admitted to hospital they will have been seen by a psychiatrist. It is the psychiatrist who controls access to bed spaces. Given psychiatrists' role as gatekeepers, their opinion of the patient's needs is crucial for the carer, yet traditionally psychiatrists sought minimal contact with the patient's family. As policy attitudes to families and to their anticipated role have changed, procedures for negotiating with and involving the newly created carers have been slow to respond. Psychiatrists are trained through a medical culture with its emphasis on the patient, and the maintenance of strict confidentiality. Doctors may be unclear as to what is currently expected from them in connection with families. Carers are also unclear about how and when to approach doctors. This was illustrated by the approaches made by the wives of patients in the 1955 study. Deasy and Quinn examined the role of the psychiatrist and found that in general

the twenty three psychiatrists we interviewed seemed to focus attention almost exclusively on their patients. They said that they initiated contacts with relatives only during the early period of the husband's hospitalisation, when they interviewed family members for the purpose of getting information about the patient (Deasy and Quinn 1955:55)

While psychiatrists recognised that relatives needed support they did not feel it was their duty to provide it. Psychiatrists in the Deasy and Quinn study felt that their duty was to provide information on diagnosis and treatment (1955:54). Little appears to have changed and while hospital staff might acknowledge the need to support relatives, no one was quite sure who would

provide such help. Attempts to provide information on diagnosis and treatment to carers were infrequent.

Bedside Manner

Carers often talked about their relative's psychiatrist and in particular about the doctor's social skills. It seems that in a field where technical treatments are less finely honed, and where it is the person's self that is damaged, the clinician's ability to communicate becomes fundamental. The manner in which the doctor conveyed information, listened, their patience, perceived humility and interest in the patient were commented on more than any technical knowledge. Carers wanted to know that their relative was being treated with kindness and respect. They gleaned this information from the relative, who might complain or become upset if they thought the doctor was abrupt with them. Carers also gathered such information from their own contact with the doctor.

Mrs L is an articulate health professional but found the consultant unhelpful. "He isn't easy to talk to and doesn't listen." She also felt he lacked empathy. On one occasion Mrs L's sister became antagonistic towards her during a meeting. Mrs L began to cry "but he never attempted to comfort or reassure me." Some indication of feeling for the carer, however basic could have made a great difference.

Mrs O's son had been ill for ten years but she had never seen the psychiatrist. It seemed that unless the carer took the initiative and sought the consultant out there was unlikely to be any contact. Mrs O was agoraphobic and also being an ex-patient felt unable to visit the hospital. A meeting with the consultant was facilitated through the social worker at an out-patient clinic. Unfortunately Mrs O wished to ventilate her feelings and asked why the consultant had called her son "a prat" for trying to commit suicide. He felt unable to address her comments and losing his temper, got up and walked out. Whether her frustration was appropriate or not, the psychiatrist's

behaviour during their only contact was damaging. Mrs O was providing considerable support to her son and needed actively bringing into the care planning process.

Power

One carer, a husband, spoke specifically about “power”. He disliked the way that so much power was concentrated in the consultant’s hands. In particular he questioned the wisdom of patients being discharged from sections of the Mental Health Act 1983 by the consultant alone (see Jones 1990: 58-59). He felt that if it took the considered opinion of *two* doctors and an approved social worker to impose a section then the decision to discharge should have a multi-disciplinary basis. This proposal can be viewed as quite logical, for mistakes might be avoided if expertise and information were shared. It could also reduce the blame that can be attached to the unfortunate doctor who discharges someone who later proves violent. Such procedures would of course be time consuming and, given the pressure on bed spaces, medics are likely to want to retain the power to ‘clear’ the wards. It would also challenge the consultant’s traditional authority.

Treatment Planning

Some carers complained that they were not given information about treatment by the doctor and felt that they were generally kept in the dark. One mother found that her sister was detached from the situation and able to be more assertive. She kept asking “what is this for, how much is he getting, but they didn’t like it”. She noted that carers feel anxious to be kept informed and lacking the knowledge of how to obtain the information “one becomes aggressive and emotional”. Carers were aware that this damaged their case but often resorted to this approach in desperation.

Junior Doctors

Much of the routine hospital care is conducted by junior doctors with overall responsibility assumed by the consultant. Junior doctors are 'rotated' every six months, either to a more senior position at another hospital, or to another speciality. The experience they gain through seeing a large number of people (symptoms?) cannot be discounted but the system is designed to fit the needs of the professional and not the service user. Each encounter with a new junior doctor involved the user and carer retelling their story, forging new relationships and gaining trust only to have to repeat the whole process with another new doctor, either at the outpatient clinic or during the next admission. Consultants tended to be more static but could also move away especially if they were locums. Part of the process associated with 'breaking in a new doctor,' especially a junior, was the difficulty in being *heard*.

To save time I had written all my partner's details down. His medication was particularly involved and there had been a number of alterations not yet recorded in the medical notes. I explained the changes carefully to the junior doctor, but he seemed unable to accept what I was saying. This did not instil confidence (Personal Caring Diary, August 1995).

Doctors and Carers

Doctors have not been encouraged to regard family supporters as carers and their training requires them to look principally at the individual and their symptoms. GPs are more likely to be familiar with the family context of illness and of families' strengths and difficulties, but they also focus on the patient. Having been tutored to respect confidentiality, sharing information and decision making with family carers will feel at best highly unethical but also an irrelevance.

My partner's psychiatrist actively involved our family, (having first sought the patient's consent) but there were the occasional awkward times when I

reported the problems that my partner denied. The psychiatrist never lost his sense of focus - the well being of his patient, yet he was able to recognise and acknowledge my pain.

Despite the respect the psychiatrist afforded me "as one of the family" ie a mental health professional, I often found my role fraught and held it with ambivalence. I do not believe this was because I was a professional, but because every carer becomes adept at recognising the idiosyncratic symptoms of their relative in relapse. I felt that I had assumed an authority that I should not have held, yet to avoid sharing my understanding could have jeopardised my partner's care (and my own safety and quality of life). We do not have a script for the performance of the caring role in mental health. Cave's research about empowering users is revealing, she describes the resentment that many professionals feel. Using the language of user empowerment she refers to the phenomenon of 'bossy carer' who tries to influence all the decisions regarding their relative and who will not permit the relative and professional to talk privately (Cave 1994:30). Carers face a dilemma, being regarded, and also perceiving themselves as domineering when being appropriately assertive.

There is ample scope for misunderstanding between carers and psychiatrists. The psychiatrist may feel that the carer is interfering, and inappropriately inquisitive concerning the affairs of an autonomous adult. The carer may feel that they know most about their relative, and that they have a right to recognition as it is they who must shoulder the responsibility on discharge.

Medication

Users appear to be regularly in disagreement with professionals over the role of medication. Being in the system inevitably involves being on medication, and this means that in the absence of close professional supervision, the carer can be forced into an uncomfortable relationship with regard to compliance. (Compliance is the medical term for doing what the doctor advises ie taking one's tablets or attending for an injection). Users often feel resentful at their

lack of control regarding medication which extends beyond periods of admission into all aspects of their life.

Barham explains that

most users did not object - in the short term at least - to taking medication, and indeed many of them found it beneficial, but they were intent upon ensuring that medication did not interfere with what they held to be the main priorities in their lives. And, it was here that conflicts with the medical profession arose. What participants looked for from psychiatrists was an approach that took account of their needs and concerns as persons - the prescription of anti-psychotic drugs was an adjunct to a psychosocial understanding of their predicament rather than a substitute for such understanding. Our participants perceived medication not as a good in itself but as contributing to some strategy that enabled them to live their lives as relatively ordinary people within the limits of their vulnerabilities (Barham 1992:61).

None of the carers of users who took medication viewed its use as unproblematic. Indeed carers were almost always sympathetic when relatives complained. One mother explained that it "is strong stuff and they don't really know what it does to you." Carers noted a range of side effects especially weight gain and sweating. There were other side effects, or presumed side effects, which carers had found professionals unprepared to acknowledge. One mother described how her daughter had experienced ocular-gyro-crises, but the professional response was that she (the mother), must have failed to follow the dosage correctly. Another user and her parents complained of her suffering from strange rashes and profuse perspiration from her feet. Others complained of users being lethargic, and being unable to stay awake to cope with a normal routine. Many carers used the colloquialism "drugged up to the eye balls".

The Carer's Agenda

As a carer I have a vested interest in my partner accepting medication but this is fraught with guilt. He takes medication for the treatment of symptoms that he finds distressing, for suicidal thoughts and obsessions, but it is difficult to persuade him to endure unpleasant side effects for the treatment of invisible symptoms (ie of which he allegedly lacks insight) such as manic irritability. In taking treatment, such as anti-psychotic medication like droperidol, he risks the possibility of developing an irreversible movement disorder, known as tardive dyskinesia. At its worst the formula equates with coercion, 'if you stop your tablets, I will not be able to live with you any more'.

Medication and Carers of People With Dementia

Medication did not appear to be such an emotive issue for the families affected by dementia. There are a number of reasons for this. There is no treatment for dementia and any medication that relatives were given was usually as a sedative, probably in order to make them 'easier to manage'. The relatives were rarely in a position to question any medication that they were given and, having a poor short term memory, were unable to formulate an intention and hold it for long enough to interfere with their treatment. It could also be argued that many older people have been socialised to respect doctors (and nurses as their agents) and unless they were actively paranoid would be likely to comply. Paranoia does affect people with dementia, and this could lead to problems when users suspect that they might be poisoned by their family.

Carers and Medication Reduction

It is usually the carer and professionals who form an alliance to persuade the user to take medication, but on occasions the carer may stand alone. Mrs AA supports her mother who is in her 60s. There is a pattern to her mother's illness, and Mrs AA resents the psychiatrist who refuses to listen to any of the family. He sees the mother alone, who insists that she is well and requests a reduction in medication. Mrs AA stresses that her "mother is cute" and can convince the doctor that she is well. Each time her mother has her medication reduced she copes for a few months and then relapses. Each relapse is followed by a difficult period where her mother becomes very disturbed but will

not go into hospital, and evades attempts by professionals to visit her. Mrs AA questioned the psychiatrist's decision to reduce the medication, especially in view of the regularity of the relapses that followed. She also resented the psychiatrist's refusal to consult the family. Relapses were inevitably unpleasant because her mother often lost insight and had to be allowed to deteriorate to the stage where she could be sectioned. "I know the signs of a relapse. I can see it coming. I don't want her to get to the stage where she is carted off with the paramedics. She loses her dignity. It doesn't have to get to that stage, it could have all been avoided".

Beneficial and Adverse Drug Reactions

It was invariably problems that carers emphasised, but for a small number of carers and the people they supported medication was virtually unproblematic. Some users agreed to take standard anti-psychotic medication and stayed well for most of the time. Several of the people in the study took the new drug for treatment resistant schizophrenia, clozapine, and, apart from weight gain, were very optimistic about the results, as were their carers.

One man's mother explained that he had suffered a severe adverse reaction to a standard anti-psychotic drug. This reaction, which she referred to as being "allergic to the medication" occurred some years ago when he was in his teens. "His body became arched and he had to be fastened to the bed. He shook and steam came off him". He could not walk but had to be supported by two people. His parents did not appear to have been given any satisfactory explanation for this episode, except that after treatment at a neurological unit, he had been lucky enough to be able to walk again. The carer's description would suggest a 'rare but serious disorder' called neuroleptic malignant syndrome following psychotic medication. It is associated with hypertonicity, hyperexia, and is fatal in 15-20% of cases (Gelder et al 1993:649-650). The consequences of this is that her son has had to endure his schizophrenia unmedicated.

Non Compliance

Some of the carers support relatives who would not take medication when in the community. Mrs X's son, diagnosed with schizophrenia, is one of the people who do not acknowledge that treatment is appropriate for them. Consequently he only receives medication while it can be enforced by Section 3 of the Mental Health Act 1983. Any periods of stability are short-lived, he is discharged and when he has deteriorated sufficiently to warrant compulsory treatment, he is readmitted. It is a vicious cycle, and he has now been subject to around 15 compulsory orders.

My partner frequently decides that he needs to try to cope without medication. Such episodes are influenced by frustration at his routine which includes over 20 tablets daily, and at their side effects, especially the diarrhoea, nausea, weight gain, and impotence. There is also the dissatisfaction with their level of symptom control. If medication constituted a panacea, the debate about compulsory treatment in the community might be rather more simple, but for many medication is a mixed blessing, alleviating some but not all of the symptoms. This can only contribute to carer's guilt. Many carers are well aware that despite the endless adjustments to medication, their relative is still ill, yet fear that unmedicated they could be even worse.

Most medics gave the impression that they felt that the issue of medication was uncontentious. They, the doctor, prescribed medication on the basis of expert research or knowledge, and the patient should behave logically acting as instructed. The term *non-compliance* betrays the medical focus. Work by North et al (1995) examines the conceptualisations held by users of benzodiazepines. In the 1960s *benzos* were widely prescribed for minor psychiatric and emotional problems. They were believed to be safe and effective. Unfortunately in the mid 1970s evidence emerged that they caused psychological and physical addiction (1995;632-633). North et al found that users did not have a neutral relationship to their medication. The use of drugs,

including prescribed medication, seemed socially unacceptable when used to influence mood and behaviour. Where dependency on dialysis or insulin is concerned, compliance and regular use is considered natural and desirable, but regular long term use of prescribed psychotropic medication was felt indicative of weakness. 'The younger employed anxiolytic users felt a degree of ambivalence about taking their medication. They saw their inability to cope with a "normal work environment" as a personal weakness and feared judgement from work colleagues' (North et al 1995:638). Users in the current study often expressed the need to be able to cope without medication, and attributed their failure to do so, to a lack of moral fibre. Recovery was seen as re-establishing control. North et al note work by Conrad with people taking anti-epileptic medication. Patients might adjust their drug dosage and be perceived as failing to comply by the medics, but 'failure to adhere strictly to the recommended regime - was for the patient a form of asserting control over one's own disorder' (North et al 1995:646). Patients appear to need a level of autonomy and will exercise this even when medics have not given them the discretion to. My partner often felt out of control and a slave to the drugs he took. North et al (1995) have advocated a typology for the relationship between users and their medication. For people with severe mental illness who are often prescribed several drugs in combination their categorisation of *master* (1995:644) was most fitting. The relationship was described by a benzodiazepine user as all consuming that the drugs "dominate your life, they invade you" (1995:645). My partner however feels he has two masters. The medication, promising control of symptoms but rarely delivering this and also exacting a price in terms of side effects, and the illness- that "fat worm devouring my brain". We are engaged in a war which feels relentless. His growing disillusionment led him to reassess the suggestion that his medication was a master, indeed he began to feel so strongly about his enslavement that he referred to the illness and medication as the *enemies*. It was apparent in the current study that users resenting their medication could feel isolated and vulnerable, surrounded by professionals (and also their carer) who advocated taking the drugs. There was a sense of desperation in their predicament.

The Amateur Doctor

The level of involvement by carers regarding medication varied. For those who had a depot injection the carer had little involvement, especially if it was delivered by a community nurse in the home. Most relatives obtained their own tablets and took them without particular supervision. Carers varied in their awareness of drugs. One mother explained that she did not feel it was her role "I'm not one of those amateur doctors". However, another father not only dispensed his daughter's medication, but also titrated the dose in response to perceived changes in her mental state. It seems important for professionals to acknowledge that carers and patients may indeed alter the dosage, especially if there is a long wait before the next appointment with a psychiatrist. Unfortunately I observed that carers might reduce the wrong element of the drug cocktail and trigger further problems.

My partner and I were entrusted with a supply of emergency medication (anti-psychotic) and authorised to use it. Ideally he could self-medicate, remaining in control and avoiding the indignity of inconveniencing a GP out of hours. This rarely worked to plan, as in times of crisis insight was usually lost and I was left to consider how persistently I should encourage him to take something. This felt unsatisfactory as, unlike taking medication for a high temperature, one's mental state can not be assessed objectively. Each crisis was mediated and manifested through our relationship and through my own feelings, tension, and a fear that I could be scapegoating my partner with my own problems. There was no easy answer, early recognition of symptoms could avoid a crisis followed by a hospital admission but the regular assessment of his mental state felt both an undesirable pressure and an unavoidable duty.

Medication for Carers

Many carers in the current study also took psychotropic medication or had done so at some stage in their caring career. Some felt anti-depressants had enabled them to endure a crisis and they had been able to cope unmedicated thereafter. Others felt that ongoing medication was a necessary crutch. One woman experienced stomach problems which she attributed to stress and another took benzodiazepines for her “nerves” but did not regard her problems as arising only from being a carer.

In order to survive I also joined the statistics and began to take anti-depressants in October 1994. Although I had experienced episodes of depression before, I had not used medication for 18 years. My need for medication was, I felt, a direct result of being a carer. There were a number of pressures on me simultaneously and, given my added problems as a carer, I lacked the resistance to cope.

Atkinson and Coia (1995:34-35) have looked at the data linking the mental health problems of carers to their caring role and find the links tenuous. Carers in this current study however were adamant that their mental health was adversely affected by caring. Such problems could further disadvantage the carer in terms of developing a poor health record at work.

Carers of people with dementia, contacted in the current study did not report using psychotropic medication. This does not mean that they found their caring task easier to perform, either emotionally or physically. It would seem probable that as the burden became more difficult for the carer, admission to hospital or residential care was instigated. This placement became permanent rather than transitory phase, as in the case of people with severe mental illness.

In addition to GPs and psychiatrists, carers also encountered a range of other professionals who might act as gate keepers to services. These professionals included community psychiatric nurses, social workers (increasingly called ‘care managers’), there was also contact with workers at the Benefits Agency, housing department and with a carer’s counsellor working for a mental health voluntary agency.

CPNs (Community Psychiatric Nurses)

CPNs were most frequently cited as being involved with the service user but their role towards family members was less clear. There appeared to be some discrepancy between the expectations of carers and professional priorities. In a review of literature concerning carers of people with mental health problems, Perring et al (1990:40) noted that carers perceived the quality of ongoing support by all professionals to be inadequate. In assessing carers' views of services one is conscious that services are primarily designed to meet the *user's* needs, not the carer's (1990:39). Carers were not just critical of the failure by professionals to recognise their needs, but of professionals' failure to help users themselves. Perring et al notes a criticism of 'frequent staff changes and the lack of opportunity for long term contact with a constant figure who knows the patient's case' (1990:40).

CPNs were most likely to offer continuity (of individual practitioner) rather than doctors or social workers. There were examples of excellent practice and trusting relationships. Mrs X said she could always "have a chat" to the CPN and raise any concerns about her son's condition. Mrs AA felt that her current CPN was excellent and liaised well with her mother (the user) and the psychiatrist. Their CPN was helpful towards the whole family, to the patient's husband (separated, but still closely involved), and to the daughter, interviewed in the study. Mrs X and Mrs AA did however stress that it had taken a number of years to arrive at a position where professionals would respond quickly to their concerns. Mrs AA also spoke of professionals working closely together and if her mother was found to avoid her injection "they went out to find her". This approach illustrated good communication between family carers and professionals but it was not typical.

In order to obtain the support of a CPN one had to pass through a number of bureaucratic hoops, and potential patients who lacked a diagnosis were consequently not referred by a GP, or psychiatrist for CPN support. This also

meant that the 'carers' were non-carers and had no professional as a point of access to the system over any sustained period. Such carers viewed discussion of CPNs and other mental health services with irritation.

Users like Mrs Q's son who led a chaotic lifestyle, and was especially in need of help, did have an identified illness (schizophrenia), but the CPN complained that he never stayed at home for their appointments. Where the user was not an eager participant in the relationship, CPNs appeared limited in their efficacy. The Clunis report has recognised the need for special teams to support mentally ill people suffering enduring problems who might also offend, abuse drugs, or lack a permanent home (Ritchie, 1994). Mrs Q felt that her son's CPN expressed frustration at the arrangements but that there were no plans to respond to her son's needs by adopting different strategies. In the meantime, of course, Mrs Q remained the defacto 'key worker'.

Dealings with the CPN proved frustrating for one carer who could not understand his tendency to 'vanish' during the user's admissions to hospital. There was a real need for the family to be supported during traumatic periods when the user was having treatment but the CPN never made contact, not even by phone. She suspected that the fact the patient was in hospital meant that he thought the user was being cared for, and that he could concentrate on other patients. The CPN was not receptive to discussing problems with the carer, yet when the carer felt the user was deteriorating the CPN was the most natural (if not the only) person to take these concerns to. Perring et al's review of the literature notes agreement that close working between professionals and families was felt essential for the well being of families and users (1990:41) but communication in the case above was non-existent.

Non communication between relatives and professionals can be frustrating, insulting and potentially dangerous. A more general failure of communication between mental health professionals themselves has been widely highlighted and was raised recently by Boyd (1996:67).

The CPN Role with the Family

Some understanding of the ways in which CPNs view their role can be gleaned from their professional literature. Current articles portray the family as a resource. Attention is also drawn to aspects of family interaction that may have a negative effect on the patient's well being. As one experienced CPN explained "we are there totally for the patient". How might this affect the caring family, given the expectation that most patients will be cared for in the community, and not institutions? Psychiatric nurses in the UK and USA appear confident about their professional knowledge, which it is claimed is not restricted to a narrow medical focus, but incorporates psychological and social aspects of the patient's care. McCrone quotes Drew who

emphasises it is in the best interest of psychiatric mental health nurses to remind other behavioural scientists, health care professionals and the public that they are prepared to offer a unique perspective because they are educated from a biopsychosocial model (McCrone, 1996:45).

The biological dimension of training is familiar and McCrone notes that technological advances (such as magnetic resonance imaging) have permitted the exploration of brain structure and function, and that where technology has ventured professional interest has followed. Nurses, she believes, need to be educated about developments in neuropsychiatry in order to explain the action of medication to patients (1996:45). The alleged social dimension to training is more elusive. Of course just because professionals claim to represent a social paradigm of aetiology in mental illness does not actually mean that this is translated into practice. Professionals (such as social workers?) who focus on structural aspects of mental distress may be even more distrustful of carers than those with a biological focus.

Nursing literature that does concern itself with the social aspects of recovery may simply reflect concern with family pathology, especially with the role of so

called High Expressed Emotion. It is also recognised that the family can provide a great deal of free support. Kumfo draws community nurses' attention to the literature concerning the role of the family in the care of its members. Kumfo observes that families will provide substantial care to mentally ill members 'irrespective of the burdens involved' (Kumfo, 1996:17). He goes on to acknowledge that work on expressed emotion has demonstrated that families can have a negative influence on people suffering schizophrenia and that traditionally families were believed to cause mental illness. Kumfo discusses the role of the family and its willingness to offer almost unlimited assistance to a mentally ill member. He therefore encourages community nurses to avail themselves of this resource and adds that identifying the strengths and limitations of families 'will not only facilitate the work of the mental health service providers, but also help improve the mental well being of vulnerable individuals and society at large' (Kumfo, 1996:18).

Using Twigg and Atkin's typology Kumfo unhesitatingly identifies families as a *resource*.

The resource model places its central focus on the cared-for person; and the carer only features as part of the background - albeit a vital resource background. Thus, although agencies may be concerned to understand better the character of this background resource through research or other forms of increasing their knowledge, they are not primarily concerned with the interests of the carers themselves (Twigg and Atkin, 1994:12).

In their discussion of carers of adults with mental health problems Twigg and Atkin noted that psychiatrists thought that CPNs could also work with the family, but that this rarely actually occurred. CPNs expressed a desire to help support carers but could rarely spare the time. It was observed that CPNs did talk to carers of older people with a dementia, perhaps because the older person could not speak for themselves. They were sensitive to the needs of

such carers but did not usually seem to have time to talk to carers of mentally ill adults, nor were they conscious of any need for support (Twigg and Atkin, 1994:112). Supporting carers was viewed as a worthy enterprise both by CPNs in the Twigg and Atkin study and by Kumfo who urges nurses to support family members in their tasks and to try to identify ways of supporting 'burdened family care-givers' (Kumfo, 1996:18). Kumfo's focus on family members is instrumental, in that support is seen as preserving the flow of free labour but his suggestion that CPNs support stressed care-givers (1996:18) is likely to remain rhetoric. Given heavy case loads and a predominantly medical focus on the patient, it is unlikely that carers will be a priority for this professional group.

Current literature suggests that CPNs are concerned with securing their role in the (technical) management of brain disease, and in using their therapeutic skills to support the patient during their cure. Concern over carers is primarily around their part in supporting the patient. It is anticipated they will perform caring tasks from a sense of kinship-duty. Literature also exists to help professionals identify and mould inappropriate styles of interaction, again to support the patient's cure. In the realm of high profile and experimental practice, there is little room for an exploration of palliative care. CPNs may have chosen to invest their energies in developing skills around the treatment of patients but many patients, especially those with long term severe illness, will need substantial *care*. This cannot be provided by a family without adequate support. Until relatively recently such individuals were often cared for in institutions. The move to care by relatives has not provoked a comparable change in the professional activities of the CPNs.

The Social Workers

Data for this study was collected both before and after the 1990 Community Care Act's implementation. Although workers were increasingly being titled 'care managers' by their local government employers, families knew them as social workers. Respondents regarded me as a social worker (rather than as a

researcher) and latterly also as a carer. It was the carer role that came to hold ascendancy. I have not included data in the study about my own practice, as this could not be adequately commented on in my presence, but carers openly criticised the practice of social workers in general, and I have included such remarks. People were familiar with specialist mental health social workers many of whom were *approved*, under the Mental Health Act, or 'ASWs'. Carers recognised that ASWs were involved in admitting mentally ill people to hospital (on compulsory orders). Carers also anticipated social services' assistance with other aspects of the user's life. This included housework, finances and relationships. There did not appear to be enough social workers to go round and this view was endorsed by at least one psychiatrist.

Simic's study about carers of severely mentally ill people found expectations of social services to be low. Of the 39 carers he visited only 13 had had contact with a social worker in the previous year. This contact was often minimal and had led to little useful change. Carers received minimal help with benefits or managing money, and mostly tackled such problems alone.

The perception widely held was that chronic illness was a low priority for social services and that those doing the work were poorly trained and motivated. Carers felt that health and social services' professionals took the sufferer's part and ignored their views (Simic, 1995:27).

Carers spoke of having had a 'good one' (social worker) who would inevitably be moved from the case or leave to work in another area. The general impression given was that most were mediocre and that "good ones are like gold". Simic noted that carers said that it took time for users to get used to "new" people, and then they would leave (Simic, 1995:28). In the current study several people reiterated this theme, and added that due to staff vacancies, reorganisations, or general pressure of work they had no social work help and had been "put on a waiting list". Carers found significant value in having someone to talk things through with, either by phone or during a personal visit.

Even if nothing concrete could be done there was a sense of sharing the burden. This service, rarely well articulated in any formal care plan, could be a crucial coping mechanism and its presence could prevent the need for expensive crisis services. Most of the carers in the current study, like others supporting people with severe mental illness, face years of caring and this makes the role of a familiar professional vital. Simic's study found very similar problems and wrote that

a major theme in carers' expressed needs was to be able to feel that someone, somewhere, was sharing the burden. Someone who was an enduring feature on the landscape and someone who knew the family problems and knew the sufferer (Simic, 1995:28).

He adds that given the perceived low status of face to face work with chronically ill people that this was unlikely to happen. A need was apparent for a "central figure" who would support the family, not only in crisis, but year in year out. Bed reduction (Simic, 1995:32), made the need for an 'effective care manager' all the more pressing. Simic concludes that there is little sign of the organisation of services responding to carers' needs, indeed more and more workers are on short term contracts and unable to promise a long term commitment. In a recent survey of people with manic depression users were asked about their satisfaction with professionals. They appeared to be very satisfied with the response of GPs, the psychiatrists and CPNs but the survey makes no mention of social work at all (Shepherd and Hill, 1996:43).

My personal impression of the opinion of 'coal face' social workers, is that most workers find enduring relationships both valuable to the client and rewarding for the worker themselves. Someone who has a relationship with the user is better placed to become aware of difficulties before they reach crisis. They are trusted, someone to whom you would naturally turn when in trouble. Unfortunately management often fail to acknowledge the need for long term work. This is understandable, given the pressure on resources and the belief

that it is unhealthy for clients to become dependent. An efficient worker is believed to be one who demonstrates a healthy throughput of work. In addition it is customary for successful, ambitious social workers to be promoted to management after 3 - 5 years of direct work. There is a contemporary debate about the need for a career structure that rewards expertise in direct work and does not regard people who choose to stay as field workers as 'freaks' (Croft and Beresford, 1995:7).

I had always valued long term involvement with families supporting severely mentally ill people but came to understand how many clients felt through direct experience. At the time of writing it is some four months since our social worker was withdrawn from my partner's case. The decision was made by management and challenged by the user, the social worker, the psychiatrist and myself - to no avail.

The times I really needed the social worker were when my partner was high and lacked insight. I could not communicate over the barrier that the psychosis caused and had an angry stranger in the house. She could talk to my partner, empathising and observing subtle changes. She would help us to plan our offensive and speak to the consultant on our behalf. The social worker was withdrawn from our care because of the decision to redraw the county boundaries. Attempts to plead with management for continuity were ignored. It is not good enough to be told that you can 'get another one', we had a relationship with her, and I missed her support. The letter came the day after he had made another suicidal gesture and was readmitted to hospital. I sat and cried (Personal Caring Diary, 1996).

When some carers were particularly critical of social workers, it was of their failure to be proactive in enforcing treatment through invoking statutory powers.

Carers felt social workers were either impotent or that they seemed unable to understand *the facts of the case* as the carer saw them.

Mrs CC felt bitter about the social workers she had seen, “they told me they weren’t trained medically, in mental illness. One told me he didn’t believe in mental illness. Just what are they trained in?”. Carers often felt they wanted ‘something doing’. To them it was clear, their relative was ill and needed help, and carers could not accept being told, that unless the patient was so ill that they could be sectioned, then “nothing could be done”. Carers added that they were puzzled as to just *how* bad things had to get before something *could* be done.

Mrs X said that some years ago she had gone to social services and had started to cry. Apparently their tea was excellent but they did not actually *do* anything. Helpful as it is listening is not always enough.

Social workers, of all the multi-disciplinary team, seem the most likely candidates to provide professional help to the family. Support of carers, though felt to be highly desirable, tended to happen in an unplanned, adhoc manner, carers almost never being given time in their own right, but together with the user, or serendipitously if the user was not at home. I knew of no cases except my own where the carer was allocated their own social worker. Carers were occasionally allocated a CPN. To qualify they had to become so distraught as to be considered mentally ill in their own right.

The Social Work Task

Contemporary social work literature construes the care of mentally ill in two major ways. Firstly through an examination of the role of the Approved Social Worker and the application of the Mental Health Act 1983, and secondly through the literature concerning care of the mentally ill in the community. Carers do not feature as significant players in either arena (see Huxley and Kerfoot, 1994, for a discussion of the future of ASWs and their role in multi-

disciplinary mental health care). Although ASWs have a legal duty to consult with and advise the nearest relative during a compulsory admission (Department of Health, 1993:8), this duty is rarely translated into an ongoing awareness of the nearest relative as a care-giver. Sheppard's study of the ASW task does not recognise the pivotal role of any carer in his risk assessment guidelines (Sheppard, 1990).

Mental health care has been encompassed in Community Care legislation but, as Twigg and Atkin acknowledge, carers of people with non-dementing mental illness were not really felt to be carers at all, at least until very recently (Twigg and Atkin, 1994:105). Given the medical dominance of mental health services, and the exclusion of carers of the mentally ill from recognition, it is not surprising that mental health social workers are less carer orientated than their colleagues in other social work specialisms.

If a discourse concerning partnership with carers is to be found, it is probably more fruitful to search in the new research concerning care in the community. The Community Care Act 1990 emphasises partnership with users and construes family supporters as carers. Braye and Preston-Shoot note that 'support for carers is a high priority, reflecting growing evidence about the consequences of a caring role. Carers are to be involved as full partners in the assessment and care management process' (1995:22). The Department of Health guidelines added that carers may also request their own separate assessment if their needs are not met by that of the user's care plan. This right to a separate assessment was strengthened by the Carers (Services and Recognition) Act 1995, implemented on April 1st 1996. Under the new legislation carers who performed or were considering offering a substantial amount of care were entitled to their own assessment. However, the needs of carers in the area of mental health may not appear to be acknowledged by social workers in the spirit of these guidelines. The reason for this may not relate solely to pressure on resources and heavy case loads. Social work literature has taken on board the oppression of disadvantaged groups, and

qualified workers value their commitment to actively challenging this. Recent years have seen users come to represent their views articulately throughout a system which labelled and condemned them to the scrap heap. Social workers identify with users who have applied social models of mental distress to question their status as damaged, sick and crazy.

Johnston writes eloquently in this tradition. As someone with traditional psychiatric training, and the benefit of being diagnosed as manic depressive after a period of psychosis, she speaks with authority. She cites the prevalence of auditory hallucinations in the general public, few of who experience accompanying distress or become labelled mentally ill. Johnston says the process of labelling is

extremely disempowering for clients, for having been given the diagnosis, they are left feeling that there is nothing they can do to help themselves, except to comply with treatment. They then also exist in a state of continual stress, for having already experienced the bizarre and frightening experience of a psychosis, they continually fear it happening again, as anticipated by their psychiatrists and books like the DSM-IV (Johnston, unpublished:10).

In aligning oneself with users one may fall into the trap of viewing 'carers' as co-persecutors, along with the psychiatric establishment. In identifying with one individual our ability to acknowledge a conflicting (complementary) perspective may be compromised. Carers repeatedly raised the issue of not being believed or having their perspective acknowledged. They experienced this as frustrating, insulting, and believed it to be potentially dangerous.

Parallel theoretical developments have taken place through the feminist critique of family therapy, in situations where men are violent to women and children. Always anxious to avoid 'blaming' any one individual, family therapy and systems approaches have now been accused of being potentially abusive.

Concepts of 'interactional causality and neutrality on which their work was formerly based' have now been re-evaluated (Mullender, forthcoming : 2). Mullender notes that the systemic model is deeply ingrained in social work practice and even when challenged theoretically may be slow to result in changes in fieldwork. Neither carers nor anyone working in the area of mental health would wish to view users of services as potentially abusive but it must be acknowledged by services that some users' behaviour causes considerable suffering to other people.

Christmas was very difficult yet again this year. His mellowness and warmth was increasingly replaced by animosity, intolerance and anger. We lived every day on the edge of the volcano and many carers will recognise the concept very readily. I wondered why I was there at all and could sense my spirits falling each day. It began to dawn on me that he had developed another episode of irritable mania but no one would believe me. I had been through it many times before, the same symptoms, he insisting that he was only being angry, and that I would not allow him to express his feelings without pathologising them. I kept asking myself if this was the case. When we talked to the social worker and CPN he was able to convince them that I was "being over sensitive and saying he was manic all the time". By the time they accepted my view I had already been ground into the ground (Personal Caring Diary, January 1996).

In asking for my view to be considered I was not claiming the right to scapegoat my partner or blame him for the interpersonal tensions. However, a systemic approach regarding the problem as arising from no one individual, but from the family system as a whole, was not only inappropriate but added a feeling of acute injustice. There was a particular stimulus present in our home and I could not avoid or cope with it. It, and it alone, seemed the obvious cause of

the tension, and when the mania was absent the family environment altered accordingly. Carers need some acknowledgement of their perspective and to achieve this does not need to involve a disregard for the feelings of the user. Any work conducted with the family should attempt to facilitate an understanding of other members' perspectives but there may be occasions when it is vital to acknowledge that the mental illness may cause symptoms of which the user is unaware.

Good Practice

Braye and Preston-Shoot discuss a case study involving a woman suffering schizophrenia and her husband who has become depressed. The assessment is informed by an awareness of power issues and by an attempt to acknowledge each party's feelings and concerns. No one person is viewed as *the* client and the worker does not side with the wife against the husband, the user against the carer or vice versa (1995:126-136). This approach is both pragmatic and compassionate. It was evident from the comments of carers in the current study that many felt their views were disregarded, especially during crises.

Workers for the Carer's Benefit

No carer in the current study had been allocated the support of a social worker in their own right and the referral of carers on mental health grounds, to health workers has been discussed at an earlier point.

Twelve study subjects were clients of a carers' counsellor. This post was a rare example of a specific carers' worker and I am not aware of others like it in the study region. There are a growing number of carers' centres but these are largely generic. Several such voluntary projects have been started in the

region where carers may go for advice, support and can be offered advocacy. Discussion with workers suggested that they were developing specific expertise in the field of informal carers and this did include the mental health needs of adults. The carers' counsellor post was created by a voluntary agency and was considered to be a demonstration project. Despite initial health funding there has been limited success in securing ongoing funding for the service and its future may be in question.

Carers who did see the carers' counsellor were almost universally enthusiastic, positive and grateful. For carers whose relatives had ongoing problems and medical support, a period of short term focused counselling on a specific issue could be welcome. One carer was anxious about a child's plan to marry into a family with a history of schizophrenia, because of the genetic implications. The carer found the involvement of someone trained and also fully conversant with the issues to be particularly helpful. For others whose relative was outside of the system, it represented the only help they might have received in coping with disturbed and distressing behaviour. The only criticisms of this service came from a woman carer who felt that at the end of the day "she couldn't change anything, she could only talk".

The general perception of specialist carers' workers was positive, and even when nothing 'practical' could be changed, carers appreciated the support. The worker provided a professional ally in a lonely environment. Given their valuable role it is difficult to appreciate why purchasers have been so loathe to fund such services. Perhaps, given the scarcity of resources, services aimed at strengthening the support of users or people who are not priority clients appears a low priority.

Support Workers

Care management principles advocate the need to move away from fitting people's needs in service 'pigeon holes'. 'This requires a change of thinking, to frame need not in terms of residential care, day care or home help, but in terms of differing levels of assistance with personal care or daytime occupation'

(Braye and Preston-Shoot, 1995:15). One way to respond to carers' expressed needs has been the innovative use of support or care workers. They may be able to carry out domestic tasks or help with the children freeing the carer to concentrate on personal support. Some carers in the current study who could have benefited from such help found it hampered by arguments about funding.

Day Services

Carers' contact with professionals led to mixed reactions about the value of day care efficacy. I do not propose to discuss this in depth, as it is adequately tackled in other work. Suffice to add that traditional day hospitals were not usually places that users or carers felt enthusiastic about. Carers might relish time away from their relative (and vice versa) but often the prospect of attending a day hospital was grim. "You realise just how far down the social ladder you have fallen when you come here." There was a lot of sitting around (as there is on the wards) and time is filled in with a quiz, handicrafts or woodwork. Users appeared aware that 'filling in the day' was no substitute for the dignity associated with holding down a paid job. This was often felt most keenly by men where tradition expects them to earn a living.

No carer in the current study supported someone who had access to an independent or voluntary day centre. Such centres are often run by professionals but with significant user influence. The Beaconsfield project demonstrates a high degree of user satisfaction (Beaconsfield, unpublished) and one may anticipate this has benefits for carers of the members but as the service is user orientated this aspect is undocumented.

Users in the current study often lacked transport, had lost their driving licence or lived some distance from a day centre. Regular day hospital attenders were often the patients requiring regular monitoring of medication and attended specifically for that purpose. Overnight respite care was absent (as noted by Twigg and Atkin, 1994:116) and the only real respite care was provided by the hospital.

Most of the services discussed, whether in the form of day care or visits by a professional, were aimed at the user. Carers were often unintentional beneficiaries of such services but had their needs met haphazardly. No one would have wished to force users to accept services. Twigg and Atkin (1994:116) note that they could not be *made* to accept respite care for the benefit of their carer. Ironically it was the very sick users who were the most likely to avoid, refuse, dismiss, and fail to attend potential sources of help. This had inevitable repercussions for their carers. This applied in particular to people who were aggressive, unsettled, who withdrew from society, and could not endure social contact.

Chapter seven

It Just Goes On and On

This is the last part to the carer's story, but its length is deceptive. After the defining experiences of the early weeks, and the process of entering the system, comes a phase that can feel (and often is) without end. This is the phase composed of the months and years where the carer's relative continues to suffer and may need repeated admission to hospital. Of course it is not like this for everyone. People **do** make lasting recoveries, they do get jobs, have relationships, and even work. Others have occasional relapses but get on with life as best as they can.

Staying Well

Mrs A's daughter has been treated with the new anti psychotic drug clozapine. She remains well, and though she does not have much realistic prospect of obtaining work she enjoys a reasonable quality of life. She travels abroad with her family and contributes to the household chores. She is usually cheerful and easy to talk to.

Mrs S's son is also being treated with clozapine and is 'well'. He lives in a flat provided by a voluntary association. These modern flats are in a residential area and have a support worker attached. He has not been able to return to university, and cannot study at the level or intensity that he achieved before the illness, but he is making progress studying at a local FE College. He really enjoys this and has remained stable for several years. He does need support, he is not 'cured', but his parents

can provide it from a distance. They are able to get on with their own lives. They provide support to other carers and are involved in consultation with service purchasers through working on various committees.

A third subject in the current study, (Mrs N's son), is also coping well and has returned to university to study. It may be coincidence but he is also being treated with clozapine. His mother has appeared anxious at times, wondering how long the recovery might last, but there is cause for optimism. Like sufferers of cancer, carers also appear anxious about relapses, their safety feels tentative and can not be taken for granted. Users of services may also feel the ever present pressure of the threat of relapse which can be exacerbated by professional attitudes. Johnston suggests

that labels such as schizophrenia and manic depression are significantly damaging to clients, probably increasing the likelihood of relapse due to a fear of going mad again and again (Johnston, unpublished).

She feels that users are under a particular pressure from professionals who warn them of the dire consequences of not taking (debilitating) medication, and also from well meaning carers who become anxious, interpreting all behaviour as being pathological, and also 'wrapping the user in cotton wool.' There is no doubt that some carers in the current study did behave in this way. Though unhelpful it could be seen as understandable.

These three users fared better than others in the study, and choice of medication appeared to have a significant bearing on their recovery. There appears to be some suggestion that less articulate and more disturbed users are unlikely to be considered for treatment with clozapine. It may be felt that they lack the insight necessary to make the exercise viable. Clozapine has to be taken in tablet form and the patient must undergo very regular blood tests. It can not be given by injection, making it hard to impose, *and* it is very

expensive. Research by the National Schizophrenia Fellowship found that 46% of the 791 psychiatrists questioned 'said their decisions to prescribe clozapine had been challenged on the grounds of cost. The figure for risperidone was 30 per cent. One psychiatrist said he had 150 patients who could benefit from clozapine, but was only allowed to prescribe to 20' (Waters, 1996:6). As cost becomes a driving force in health care decision-making it is likely that those felt to be less likely to benefit will lose out. Psychiatric patients are already considered to suffer from a disorder of moral fibre, and are not the object of concern except to the extent where they threaten public safety. One does not need to use expensive antipsychotic medication to control disturbed people. Older, cheaper medication will carry out this role quite adequately. Given the experiences of many of black men in the psychiatric system, the use of heavy sedation, compulsory treatment, and high rate of psychotic diagnosis, it seems highly likely that the poor; women; older people; and black people, especially afro Caribbean men (Littlewood and Cross, 1980) (Chigwada, 1991) (Cresswell, 1993) (Prins, 1993), will be less likely to be selected for treatment with the more effective and humane modern medications for schizophrenia, and that they will be controlled with high doses of older drugs, which may have many side effects. Further research is needed to clarify this issue and there is an argument for people with severe, long-term mental illness to have their treatment funded on a regional basis, rather than allowing them to become 'hot potatoes' to be rejected from GP fund holders' lists.

The Ones Who Don't Get Better

One of the defining (and perhaps most cruel) aspects of the human condition is our ability to project despair into the future. This final phase in the Carer's story is especially concerned with hope and despair. Medicine is primarily concerned with finding a cure, and the challenge of new acute conditions. It is far less orientated to the *care* of those with so called chronic disorders. For families of people with severe mental illness this latter phase may be the most difficult and in terms of time will easily predominate. The majority of carers in the current study support people who have failed to recover to any significant

degree. It is perhaps fitting that I am writing this chapter some two and a half years after the onset of my partner's current illness and at a time when his suffering seems interminable (in March 1996).

Battle Fatigue

When discussing the experiences of carers of mentally ill people a research psychologist I encountered commented on noticing an *absence* of distress. Literature acknowledges that distress in carers of this group fluctuates intensely and I have previously mentioned how one carer discussed her 'good and bad days'. By gathering data through 'snapshot' interviews one may form a misleading impression.

It has frequently been noted that relatives tend to understate their problems. There are many reasons for this. For example the severity of the disorder fluctuates. If things are all right at the time the interviewer calls, the course of previous events appears more tolerable and crises which were agonising at the time tend to lose some of their urgency (Greer and Wing, 1980:19).

This fluctuation has revealed itself particularly in the reflexive material.

If you asked me about things I'd still probably be able to joke but on the bad days I am lost for words to express my feelings. I feel that I should telephone the new Social Worker but I don't know what to say. I could not articulate my needs or his at this time and I really need some one else to do this for me. The social services are reactive and wait for us to go to them rather than enabling us to ask for help. When I do ask the answer has always been 'no'. I juggle home care, work, supporting our son and nursing someone who is chronically and severely ill, but I can not physically do this indefinitely.

No one has any answers and we know that no one is to blame. We have graduated to a cocktail of medication that has caused a reduction in his ability to fight infection. He looks dreadful and often cries when I leave him to go to work. We are now waiting for a bed in a regional unit under the professor's care. There is a new name for the parasite - a schizo affective disorder. Apparently his illness is so complicated he is regarded as a one-off diagnostic wonder.

We lunge from crisis to crisis - from fearful nightmares and an inability to sleep more than two hours per night to complete lethargy. I need the energy to listen and to comfort him but unless I get a break and have someone to share this with, I end up depressed and exhausted. My distress only adds to his guilt. The irritability is gone but now he has no quality of life at all. Is this what we do to them? Why isn't there a mid-way between madness, anger and a chemical strait-jacket? I already know the answer and for many people there is such peace but not for us, not yet. Do you remember how afraid I was of ECT? - the other week they calmly but deliberately mentioned psychosurgery (Personal Caring Diary, March 1996).

I suggest that many practitioners will not access such feelings and may be ignorant of the intensity and duration of distress amongst carers. Where such distress exists it makes a mockery of 'care in the community' and requires a committed application of practical and emotional support. There are obvious reasons for professionals not accessing such distress. Pressured by a heavy workload it is wise not to seek additional work. One does not phone carers to ask how upset they are, or to offer appointments, one waits for them to phone you. With any luck the crisis will have faded by the time the professional is

able to return the phone call or arrange an appointment. Professionals are not callous but must survive: to acknowledge the distress experienced by family members would lead to an immediate doubling of one's caseload. This occurs at a time when the lack of resources has already squeezed services and forced managers to allocate additional work to practitioners. Practitioners respond by ignoring routine or preventative work and responding only to crises.

If the distress of carers is hidden, how can one access this? Lofland (1971) suggests unambiguous questioning. This has traditionally been suspect and viewed as prejudicing the subject's answers but it can be appropriate. In the current study people rarely spoke specifically of their distress, except towards the end of the taped interview when they indicated that the conversation had not tapped the intensity of their experiences. When I did ask direct questions the reply was very often matter of fact. "Of course I'm worried, of course I feel like I've had a bereavement, yes we have lived through hell." Other carers that I visited frequently did begin to talk of their distress. Much of the communication that goes on between carers is non-verbal or reflects the minimal responses used to indicate that one understands. It is not until professionals become more proactive in helping carers express their feelings that they can begin to embark on conducting an accurate assessment of carers' needs.

In the Longer Term

The people who have fared best have been discussed. Their relatives continue to be part of the system with its appointments and sick notes, but the illness does not dominate their entire being. Such relatives and carers live other roles and have cautiously developed a sense of 'normality'. Of course this normality is always tentative.

Information from the study families suggests that most were less fortunate and for them coping with things 'going on and on' was the biggest challenge. Information about some carers was limited to a single snap shot interview, others I saw at regular intervals continuing to play a role in their support. News

of some families continues to come through the 'informal carer network' (March 1997). Carers pass on messages and tell me how people are doing. Sometimes they want to ask advice but the contact is now also social. There was always the option to re-visit families but in some cases this would have felt intrusive. Where a recovery occurred many families sought to put things behind them and distance themselves from the system. Where a user had committed suicide, deliberate involvement would have been abusive. Each carer's story is unique but there is a sociological thread running through the experiences. Carers can recognise in each other the stages of fear, optimism, misery and the day-to-day fight. The information from my own experience is individual, but I believe that it provides in-depth insight into the processes involved in caring in the longer term. The data derived from months of caring, many, many visits to doctors, psychiatrists, CPN, and social workers, plus and the daily family discussions provides a tentative map by which one can begin to explore the experience of long term mental ill health. From this data one can start to ask questions, 'What made things worse, what helped, what strategies were adopted and how have families managed the continued assault on the integrity of their lives?'.

Many carers noted a time when they realised that the problem was potentially endless. This often came after several 'episodes' (recoveries and re-admissions). When your son is only twenty this is obviously a shock. Aspirations for your child's marriage, career, for your own retirement and independence in mid life are threatened. Depending on the length of time between episodes, planning for next year, next month or even the weekend will always be tentative. Counselling around this crisis of meaning appeared absent for both users *and* carers. Johnston (unpublished) notes that when faced with other forms of severe illness or disability patients are normally afforded counselling support. The need for counselling around the impact of this illness and/or the diagnosis is ignored. Somewhere there is the unspoken message that once recognised as severely mentally ill, especially if the 'S' word is used (schizophrenia), one has already relinquished the claim to one's

humanity, A *schizophrenic* is not a person any more, they are just that, and as such have no feelings, dignity, future or worth. Such beings do not require counselling as they have nothing to lose. What is true for the user also applies to the carer. The carer may suffer initial feelings of sadness, but should adapt their expectations realistically. This means accepting that their child, partner or relative is not (and never really has been) a human being at all. Textbooks encourage carers to come to terms with things, to accept the situation.

Kuipers et al discuss the value of helping carers face their loss and of doing grief work. They also talk of techniques for helping the people who will not do the 'honourable' thing and let go of the person who might have been. For families who hark back to the past they suggest 'the therapist's job is to lower the expectations by educating them about the effects of the illness' (1992:54). No one in the study was able to speak of having received such counselling either formally or in an ad hoc manner. Although the need to acknowledge grief has increasingly been recognised it remains low priority. One carer spoke of the depression her son faced, this was she felt a reaction to his illness and to the destruction of his talents, but this process went unacknowledged by professionals. Focus was much more likely to be on changes in medication or the management of some alteration in symptoms. Social workers were no more likely to tackle 'loss' issues than were health workers. Although the reality of *loss* may be recognised academically, it has made little impact on the practice in the study area. The prognosis was not usually offered explicitly by professionals but its reality emerged in the way that an understanding of the terminal nature of cancer might develop. Carers might ask professionals if "this is it, surely he must get better than this". They noted that other people outside of the immediate family stop asking how they are. Carers felt that people wanted to hear good news or at least about something different, but many users' problems possessed an unbelievable tenacity and smouldered on remorselessly. The carers and the users themselves often felt abandoned at this stage and felt they received less professional contact. They believed that

the psychiatrists, nurses, and social workers had become bored with them: after all, the term chronic is used colloquially to convey such sentiments.

Chronic Patients

Health professionals construct longer term illness through a model of chronicity. Such 'cases' are felt to lack challenge and also present a poor opportunity for therapeutic endeavour. They are often relegated to the case loads of nursing and social work assistants rather than to more skilled staff. Scott et al (1991:232) write about the treatment of 'persisting disorders of mood' and note that it is tempting to scapegoat the patient, thus someone with an enduring, treatment-resistant depression can be seen to possess an intrinsically negative personality or to lack the motivation to recover. Although theoretically working from a superior social paradigm, social workers also have guilt-absorbing strategies for dealing with 'regulars'. Repeated presentations are regarded negatively and with some superiority on the professional's part, as illustrated in Mitchell's work (1993). Carers experienced a lack of dignity in having to repeatedly seek professional help, yet if users are to be cared for in the community it is vital that they and their families can seek advice with confidence. This aspect was noted by Cox and Greenwell (unpublished) who said that carers felt that the mention of their name at the surgery must have caused staff to despair.

Dementia Caring in the Longer Term

The prognosis for dementia was usually clearly spelt out to carers at the point of diagnosis. It was described as a process that led unquestionably towards deterioration and death. What remained uncertain was the very individual path that each family would tread and how long that might take. For the people that I spoke to, dementia has usually come after a life long relationship and offering care felt like a parting gift. There was often considerable pride taken in "keeping them at home and in giving them the best". Traumatic as the bereavement would be, or had been for some carers, it appeared easier to accept when it took place in the context of the best care the family could offer.

Mrs F, whose husband developed an early dementia had been able to take great pride in the care she offered. "I was confident that I could give the best." Though not professionally trained, she mastered all the necessary skills and turned and tube-fed her partner until his death. She feels she is left with positive memories and without guilt, despite her very tragic loss.

Carer-Burden

As previously noted, most literature concerning carers has focused predominantly on carers of older people and on parents caring for people with a learning disability. It has concentrated on discovering the secret of 'successful' home caring and of how to maintain such arrangements. Bergmann noted that it was important to time professional help to prevent families becoming exhausted and abandoning their commitment. Bergmann produces diagrammatical evidence to convince professionals of the value of providing support in sufficient quantities, before rejection occurs. Apparently too little, too late, is often met by ingratitude, and can not help if families have already made irreversible decisions (1979:54).

Perring et al (1990) note that by attempting to quantify the problems of carers through the use of measurement techniques, writers have sought to produce objective evidence that can sway political bodies. Allegedly anecdotal comments from distressed ('neurotic' women?) carers do not hold sway in such circles. Yet the construction of burden measurement scales and the use of instruments that purport to identify carer distress and psychiatric morbidity can feel offensive to carers. Some carers in the current study were privately angered by such approaches. Unless it declares a clear commitment to improving the quality of life for carers and their families, such quantitative research may appear calculated to exploit carers as a resource. The implicit agenda being that help is given only where rejection of the relative by the carer, may occur, since such rejection would prove costly for the authorities who might have to fund residential care. These instruments focus on the theme of burden and recognise its *objective* and *subjective* dimensions. Objective

burden relates to taking responsibility for tangible tasks such as cooking, cleaning, dressing, toileting, feeding and obtaining finance. Subjective burden can be associated with the degree of objective responsibility, but need not be. Researchers have attempted to locate mechanisms for reducing subjective burden (without any alteration of objective burden). Brodaty and Gresham (1989:299) devised a 'training programme' for carers which, they asserted, 'can reduce the psychological morbidity of the carer and delay the placement of the patient in an institution without increasing the use of health services by either patient or carer'.

Caring and Chronic Physical Illness

Other work concerned with carers has explored chronic and severe illness in younger adults and its effects on the family. Corbin and Strauss' qualitative study entitled 'unending work and care' attempts a theoretical re-evaluation of caring rather than an attempt to demonstrate the quantity of burden. They believe that although there were arguments against using illness as a defining concept given its medical basis, there was enough evidence to support making useful comparisons between people suffering a variety of problems. Corbin and Strauss discuss the process of coping, balancing and managing that they term 'accommodation.' It is this expression that seems to more adequately reflect the carer's experience in the current study rather than phrases like burden, especially where caring occurs in the longer term.

By accommodation we mean the day-to-day struggle of spouses to keep some sense of balance and give meaning to their respective lives as they attempt to manage a severe illness. This struggle involves a constant juggling of time, space, energy, money, jobs, activities and identities. For example there is the paradox of coping with mutilating surgery and at the same time feeling grateful to be alive (Corbin and Strauss, 1988:6).

They also note that carers may wish to be free of their responsibility and yet want to care, be grateful for outside help yet want their privacy back (1988:6). Corbin and Strauss seem to capture the *dynamic* aspect of illness management. They add that intervention (one assumes both social and medical) should ideally be unintrusive and may still disrupt privacy, independence and autonomy. Families in the current study were both pleased to be helped but lived public lives, their families providing the material for psychiatric activity.

Cox and Greenwell's work looked at people caring for those experiencing a variety of problems. They observed that non-carers really did not seem to understand 'how much the disability (sic) sets the agenda' (Cox and Greenwell, unpublished:17). They also note that the media may portray carers as saints, yet the carers seem universally affected by guilt. Somehow, somewhere, carers (women?) have taken on the adage that they must love and care perfectly. Caring should be wholly altruistic, devoid of the resentment and impatience that quite naturally arises with tiredness and in real not idealised human relationships. Their evidence supports the suggestion that in the area of mental health it can be the *inability* to care that causes guilt. A woman explained how her son, who suffered schizophrenia, was discharged home to her. She was offered no help, and when she said she could not cope, the police were called to send him away. He then lived rough for five weeks (Cox and Greenwell, unpublished:23).

Caring and Mental Health

As previously discussed, much of the literature concerning 'caring' does not fit comfortably with carers of people with mental health problems. The caring tasks are not clearly recognisable, where they are identifiable they may hold different significance. Carers can be accused of exaggerating or being over-protective when they articulate their responsibilities. Women, especially mothers, are vulnerable to such accusations and a snap shot assessment of the relationship with an adult suffering mental illness may appear to reveal

over-protectiveness, even a stifling of independence. Professionals fail to observe a dynamic process that may have arisen over time, whereby the carer has gradually assumed an increasing degree of responsibility. Twigg and Atkin (1994:122) speak of carers becoming engulfed by their caring task. They note that many are 'engulfed' because of their objective burden but that others lack such responsibilities. Failure to accept the extent of responsibility that carers feel can become oppressive in that professionals may use this (at least unconsciously) as a defence against requests for help. The situation is further compounded by the way in which mental ill health can fluctuate, and a service that responds slowly, (because it is geared to the more static needs of people with dementia or a physical disability), lags inadequately behind changes in need or insight on the user's part.

How do People Cope?

Given the observation that some people do actually cope better than others, previous research has attempted to identify the salient variables. The question is inevitably methodologically complex, perhaps some people just cope better with all life's problems! Research has attempted to identify coping styles and to instil particular techniques into the repertoires of carers who struggle to cope. The underlying flavour of such training programmes appears to reflect concern for the welfare of the service user. The lessons acquired from the experience of the study of high expressed emotion in carers of people with schizophrenia has been translated to the situation of carers of older people with a dementia (see Bledin et al, 1990). One of the main findings of such research was that carers reacted negatively to behaviour that appeared to be under the sufferer's control. Incontinence and repetitive comments lead to irritation and criticism. A programme providing information about the illness could help carers reattribute blame and was demonstrated to produce a reduction in critical responses. Professional activity in mental health has often focused on the recognition of such dysfunctional styles of coping. Wilson has produced a booklet aimed to provide relatives in this region with helpful information which can assist them in caring for people diagnosed with schizophrenia. Written in an accessible way

it acknowledges families' frustrations, and is informed by the high expressed emotion model. The booklet suggests creating firm boundaries for acceptable behaviour by the users, keeping calm, creating a structure of activities and chores, praising welcomed behaviour and avoiding arguments (Wilson, 1996). The advice is admirable and can only help improve relationships between carers and service users. It is practical but possibly idealistic. One of the difficulties that carers face in the longer term is the lack of reciprocity in their relationship. As in a professional relationship, the carer must attempt to never be unreasonable, irritable or demoralised. To achieve such a standard in one's private life is difficult, especially as carers are asked to bear the burden alone, without a colleague to moan to! Carers of people with enduring mental illness in the current study and in other research (Greer and Wing, 1980), acknowledge their frustration, as a service user may sit all day and show no motivation except when continually prompted. A carer may **know** that this behaviour is associated with the illness but still **feel** like screaming!" The professional advice given in the high expressed emotion programmes advocates that carers behave like sponges.

Carer Strategies

Carers in other research, and within the current work, identified conscious survival strategies. These had often been developed painstakingly over the time rather than through professional guidance. For some carers, groups provided advice and support. Self-help groups appeared useful at particular times in their caring career, particularly around the time of first diagnosis, when the carer was struggling with the meaning of the diagnosis and wanted to meet people in a similar situation. Also, groups helped at a later point, often after a recovery and subsequent relapse. These carers who did attend self help groups suggested that they were a useful tool to help one over a crisis, or even for a couple of years, but in the longer term carers often began to feel unsupported by attendance. One *user* explained that going to self help groups became unhelpful. He found them depressing, particularly as all members had in common was their illness. He often felt demoralised when a member

relapsed and needed readmission. For both users and carers contact with others in a similar situation causes ambivalence. There is support and safety of people who understand, but the hopelessness of one's own situation may be reinforced by observing the effects of the illness on other people.

Self Help Groups

Groups are often advocated by professionals. They can be legitimised with a succession of jargon terms, such as peer support, user empowerment and the raising of self esteem. They are, of course, cheap, and half a dozen carers who might not be high priority for social services can be serviced in this way. Carers who attended groups often did so for a limited period but some expressed an opinion that they continued to attend from guilt, and no longer received any tangible benefit. Others, who were sole carers, who lacked transport, and could not leave their relative alone, found the attendance unrealistic and regarded it on the same level as suggestions that they should have a night out, or take a holiday. Well meaning professionals might suggest that they 'just go' which seemed impossible for the carer to contemplate. They explained that even if they did 'just go' they were unable to relax as they never knew how things would be at home.

Some carers specifically said that they did *not* want to meet others in a similar situation. They could barely cope with their own family's troubles and could not stomach further distress. People sought to retain meaning in *their* lives. This was particularly fragile, but to expose their vulnerable stability to further threat was unthinkable. One woman with cancer explained, "when I sat in the waiting room at the radiotherapy centre I did not want to know anything about the others, I know it sounds awful but some of them were dying and I did not want to think about my own future." This sentiment was repeated almost word for word by the carer of a young woman with schizophrenia. Supporting others is a viable strategy for some families but not for all. Groups should not be regarded as a panacea. One mother said she consciously explored strategies in coping. It was difficult to know when to "bully" her daughter to make her fight, or do

things for her and when to offer sympathy. She experimented with different tactics, though she took no pleasure in having to adopt a calculated approach.

Living Apart

One of the most obvious strategies carers adopted was to live apart. While it is socially acceptable for adult children to live separately from their parents, carers often felt cruel about making the decision. This was particularly so when they had sons or daughters who lived in very basic accommodation or in a hostel. The relative might be less than eager to return after a home visit. Being separated physically did not stop many carers from worrying (as Greer and Wing (1980) noted) but others were realistic and tried to recharge their batteries when their relative was away. One mother expressed her dilemma in that she wondered "if I will ever have a life of my own, I cry when he goes but can't stand having him all the time. I can't cope but I feel as though I should be able to".

Even those who theoretically lived apart could not count on their relative staying away and visiting them at arranged times. Impromptu visits, usually when the relative was upset, spent up or angry, made it difficult to invite people to the house. "I only invite people who know in case he turns up".

Despite the problems, several carers emphasised the need to care for oneself. This involved taking time out, having a holiday and developing interests. This comment appeared to almost contradict other statements made by carers about their commitments.

Living separately was not an acceptable solution for people who were married. Separation could be condoned through a hospital admission but to leave one's partner, even with good reason, is usually considered to signal the end of the relationship. As previously discussed, one couple had separated because of the illness but continued to see each other nearly every day. Even after separating the carer felt unable to diminish the feeling of responsibility. Several children described their non-mentally ill parent as wracked with guilt. Of course many partners who did leave had often done so years earlier and were not available to be interviewed as 'carers'.

'Nursing' Mentally Ill Relatives

Longer term mental illness, such as schizophrenia and bipolar disorder, might also be associated with what is commonly professionally and colloquially termed *nursing*. Additionally, people with functional mental illness also often experience a significant increase in physical illness. Whilst more caring was focused around support and the maintenance of 'normality' some users required very active personal help. This ranged from the supervision of changing clothes and personal hygiene, to prompting during meals. Some users could not make their money last and would spend it immediately and then agitate for additional funding. In some cases this situation was not limited to occasional acute periods of illness but proved long term. Attitudes by the benefits agency and hospital to money for home leave could be inflexible. At times it felt as if carers were required by the agencies to manage their relative's finances but were supposed to do so in a completely invisible, unobtrusive way and had no formal authority to do so. In one extreme case the carer was the formal appointee.

'Nursing' support is exemplified by the experiences of the woman whose son was incontinent of faeces. This situation was at best almost unbearable and any deterioration in the carer's health was potentially disastrous. Having left hospital after having an operation Mrs L had to return to washing soiled carpets. The agencies appeared unaware or unable to respond to such crises, the process of seeking help being prohibitively cumbersome. It is not always easy for people with mental ill health to attract help for physical problems. Complaints of pain may be regarded as entailing exaggeration. Everything the patient does or says is compromised by their diagnosis and may be filtered through a belief in their inability to tolerate discomfort or cope with life's little ups and downs.

My partner also required care for his deteriorating physical health. As the illness progressed so he began to look different. The drugs themselves were no cure, and extracted a heavy price in return for limited efficacy.

At first his feet began to ache and they began to turn purple. A rash gradually appeared and spread all over. He made several visits to the doctors who felt it would soon settle. It was impossible to tell if he was so sleepy because he was depressed, over medicated or ill. When he was admitted nurses initially viewed his behaviour with suspicion. I pleaded in vain that he did not usually spill drinks over his clothes and wait for me (the over anxious, smothering carer) to change them. Eventually as his skin deteriorated and confusion set in he was transferred to a medical ward. An apparently rare drug reaction was made worse by the complex cocktail of medication. It was impossible to imagine which drug was the culprit. As he dehydrated he developed toxic confusion and a potentially fatal lithium toxicity (Personal Caring Diary, March 1996).

This illustrates how one's status as a mental patient pervades all aspects of one's life. Physical disorders can be encapsulated (eg chest pain), or definitive (eg multiple sclerosis) but mental illness is all-powerful: labelling, predicting and excluding the user (and their family) from acceptance in a variety of situations. Qualitative research, such as the current study, provides a richer interpretation of the caring experience than attempts to measure 'burden'. The 'burden' research does not apply so readily to the situation of carers of mentally ill people. Twigg and Atkin (1994) discuss caring in this context as the *responsibility* for a person's safety and to this we might usefully add the weaving and maintaining of a protective cocoon that affirms normality. The carer anticipates abnormality and intervenes to protect, hide, and at times deny. This requires considerable energy and commitment as the threat of instability,

pathology, and of changes that threaten the family's claim to humanity are ever waiting to appear. So the carer's responsibility is to prevent the disintegration that would ensue should the illness be left unchallenged. It is difficult to convert such responsibility into quantitative caring tasks. It **can** involve cooking, washing, and offering emotional support but the purpose behind these activities is somewhat different, as they are carried out in order to preserve the integrity of normality within the family's life. Caring tasks are symbols of regularity, predictability, familiarity. They are the antipathy of everything that severe mental distress comprises.

However, professionals should be attuned to the fact that at times mental health carers will be engaged in more traditional physical caring: in cooking, personal care, changing clothes, and soiled bedding, as well as in the maintenance of a symbolic normality. Unfortunately, professionals may fail to acknowledge the changes that can occur in the family's needs. A snap shot impression may suggest a carer who is over-protective of a seemingly healthy, self determining adult, and professionals may be ignorant of the physical tasks carers perform for someone who is theoretically able bodied, but functionally disabled.

Relationships and Successful Caring

A common sense approach suggests that caring occurs within the confines of a pre-existing relationship, (see Twigg and Atkin, 1994) and that caring for a much loved sister or partner with whom one has had a life-long reciprocal relationship is likely to be more satisfying than the care of a previously domineering or sexually abusive parent. In the current study, although the number of dementia carers was small, two respondents spoke of the "lovely nature" of the person with dementia and of their commitment to care as a final loving gesture. Of course most relationships are not ideal, and are likely to entail some guilt, anger, and regret. The carer may have a need to put such issues to rest, even though the service user can no longer appreciate their concern. Sadly, the current research has emphasised the way mental ill health

threatens and distorts relationships including good ones. Hence there were few intact relationships that could support the provision of family care.

Gilhooly's research, on the impact of care giving on supporters of people with dementia, noted that Newbiggin found that carers who had given support for a longer period were not more likely to be depressed, but were likely to suffer poor morale. Gilhooly also draws attention to substantial evidence suggesting that caring for people with a dementia or other *mental* disorder is more stressful than caring for someone with a physical disability (Gilhooly 1984:35).

Gilhooly drew attention to the differences between men and women as carers. She found that though there was no difference between the mental health of male and female carers, the women were more likely to possess lower 'morale' (1984:41). In interpreting these findings she noticed that the men seemed 'less emotionally involved with their wives and mothers' illness than were the female supporters. Furthermore, they were more willing to go out of the house leaving the dependant unattended' (1984:41). Not surprisingly, Gilhooly observed that a complete psychiatric deterioration in the carer would be likely to force the services into terminating the caring arrangement but poor morale would not. This raises concern over what degree of responsibility society should place on its informal carers.

Distressed or Depressed?

Other research has considered the question of carer depression, mental ill health and poor morale. Eagles et al explored the mental state of carers of dementing and non dementing elderly people with two instruments, the General Health Questionnaire and the Relative Stress Scale Questionnaire (a well validated measure of mental disorder). They found carers living with an older person with dementia, were likely to suffer stress, and that this rose in response to the degree of dementia but such carers were not more likely to demonstrate mental ill health (Eagles et al, 1987:29).

There appears to have been considerable debate between theorists as to the conceptual status of the carer's expression of suffering. Eagles et al concluded that their data suggested that carers do not need psychiatrists and that 'the task of "supporting the supporters" can appropriately be left in the hands of the voluntary agencies and primary care teams' (Eagles et al, 1987:297). Are carers stressed or depressed, does it even matter? It does matter to professionals from a health orientated background who may advocate biological treatment for a 'depression', ignoring the carer's insistence that their mood is an understandable response to an intolerable situation. Fitting et al go further and use Blazer's rather jargonistic term 'transient dysmorphic state' (1986:250). This attempts to describe those terrible days or moments when carers are filled with the feeling that life can't really get any worse. Carers might feel that drawing a distinction between illness and despair is meaningless, even patronising. It alludes to a complacency with their suffering and a crude exploitation of people who are stressed to their very limits.

Given the current political context and the use of statutory resources to absorb only residual need, the mental ill health and distress of carers becomes an important issue in the evaluation of the invisible costs of informal care.

The Cost of Caring for Women

Not only are women carers more likely to experience low morale but they are also often disadvantaged financially, being more likely to be sole carers than their male counterparts, and more likely to have a low income (Evandrou, 1990:abstract). Evandrou quotes the 1985 General Household Survey, which noted that the proportion of male carers was only slightly less than that of women, with 15% of all women acting as carers and 12% of men (1990:5). Evandrou noted, however that the nature of the caring carried out by women differed, and suggested that women might take performing certain tasks for granted (ones which men might regard as 'caring') and might therefore underestimate the extent of the care they provide (1990:30).

Women are caught up and ensnared by caring, and it is they who appear to be bearing the brunt of the policy makers' economies. In the current study many parents cared as couples but lone carers tended to be women. Even within the relationship women seemed more likely to offer an involvement that their husbands or other children would have disapproved of if they had been aware.

Roles performed by women have altered considerably with them working outside the home but women in the current study could often find themselves being role jugglers. Alice Home refers to 'multi-role women', (Home, 1993). (She adds that these are women who may be student nurses or social workers while trying to manage their family responsibilities at the same time). As the state withdraws from providing institutional care for severely mentally ill people so their support becomes another role to be added to the list that women carers must cover. The current study suggests that there are not armies of neighbours, friends, or even close family prepared to share this burden. Rather than share in the care-taking, potential co-carers apparently react by withdrawing. The additional care received was frequently in the form of acute in-patient care.

Some users in the current study lived in hostels or supported flats but no one could cite an example of the provision of a family support worker, befriender, or substitute carer. Home help was being provided in just one case. When carers could no longer manage, their relative was admitted if deemed ill and willing to accept admission, or sectioned if severely disturbed. This appeared to be the only response. Stressed carers were expected to make do, or withdraw their support. This could mean asking a sick person to leave home or a carer even moving house to avoid contact.

As literature has suggested women appear particularly enmeshed in the emotional aspects of the relationship. They are unlikely to want to withdraw, nor should they be expected to. Gilligan, referenced by Fitting et al (1986: 248), commented on the ways in which women appear to place a 'stronger emphasis

than do men on their personal relationships'. Gilhooly (1984: 41) found women supporters of older people with dementia more 'emotionally involved' with the supported person's illness than male carers. This problem is epitomised in the current study by the situation of one mother, Mrs Q. Her son remains inadequately treated. He is abusive, violent, drunken, and unable to manage living alone. Too difficult for staff, his only real support is his mother. The psychiatrist is not prepared to use the Mental Health Act to treat him, and will not allow his mother to describe his behaviour unless her son is actually present. As he appears angry and suffers with paranoia, as many schizophrenic people do, his mother is too afraid of him to do this. When she has spoken openly or written to the psychiatrist this has not resulted in any positive action.

How professionals may respond to this case depends on their interpretation of his behaviour. If the son is angry, violent and unable to support himself and chooses to live that way, then that is his affair. His mother must accept the life he chooses and, having tried to persuade him to change, either ignore him or accept his aggression. On the other hand, if he is ill and this form of illness is associated with irritability, abusive comments, violence and a lack of self care, then his mother must ask for help because he can not. To fail to give him all possible help must suggest professional negligence. (Yet such a failure to carry out professional responsibilities appears widespread according to subjects in the current study). People like this woman and her son are not uncommon but such situations are difficult to work with and require considerable determination. Whether this commitment is present appears to be down to the professional's individual personality, not to national standards of care.

Apart from the difficult decision that women carers face about actually caring, there are the physical restraints of time and energy. Carers explained that no one knew from one week to the next what their relative might need. It was completely unpredictable. A relative might be fine, then suddenly say or do something that would mean they could not be left alone. Some relatives would

be up all night and carers felt unable to sleep in case they set fire to something or took an overdose. These episodes usually ended but tended to recur.

Literature has commented on the difficulties that carers face in earning a living while supporting someone with care needs. Baldwin and Glendinning (1983; 57-61) noted the pressures on women with disabled children, who needed work, but had to find work that fitted around their responsibilities. Carers in the current study spoke of the problems of 'hanging on to their work', if they had a job, of caring for other family and then having to drop all but the essentials when a crisis occurred. One mother described 'dumping' her suicidal son with her ex-partner so she could go to work. I resorted to installing my parents (both in their seventies) as substitute carers in my absence. None of the carers had been able to access responsive domiciliary care to support them in this role. One carer did try to discuss a flexible arrangement with social services but was told that agencies were organised to respond to static, predictable needs and could not meet the fluctuating crises that characterise severe mental ill health.

In a 'flexible' labour market, where only people who are fit, available for long hours and who are mobile are likely to be attractive employees, carers are inevitably going to be penalised. In the current study caring couples often accepted that the men worked and the women remained at home. In some cases the mother had worked in the past but the cost of caring gradually took its toll and she might withdraw from paid work following the emotional turbulence of their relative's illness. Others were affected but had to work. It is impossible to anticipate how their careers might have gone if they had not been carers.

Caring has affected my career. It has provided material for this research and 'credibility' with users and carers but I could have coped without that. We are not geographically mobile. Any move would destabilise my partner's fragile social support, involve a

stressful physical upheaval and involve a complete new package of psychiatrists, CPN, GPs, hospitals etc. I also have my own supports, people are used to my problems and I would lose all that. Besides who would want to employ me knowing the drain on my emotional and physical resources? My health record shows periods of sickness to do with anxiety and depression and I do not currently anticipate stopping anti-depressant medication. I would like to research abroad but he would not get a visa, in fact we can't even risk a holiday too far from a good hospital (Personal Caring Diary, April 1996).

Carers in the current study give willingly, and would not have it otherwise but there is a resentment that some of the pressure is not alleviated by appropriate state support. As one carer said, "I feel it killing me." Women are particularly vulnerable and the withdrawal of state intervention is having direct costs in terms of their physical and mental health. Such costs are not immediately obvious and may simply show up (hopefully) in some one else's budget. As the costs of production are only truly appreciated when the impact of pollution and the drain on natural resources are considered, so the implications of community care policies may be found to have far reaching consequences. I am not arguing against caring for severely mentally ill people in the community within their families, but asking for consideration of the effects on the family's physical, financial, and emotional resources. Have policies really acknowledged the realities of paranoia on mothers of service users, of self harm on younger siblings and of how carers can be expected to provide what at times amounts to 24 hour care?

The long term problems of caring are not always so different from the sudden crises which plunge families into involvement with the system. It is appropriate to end with a discussion of aggression, risk, and self harm. Surely these crises are endured and then left behind? The shocking reality is that for many of the

families in the current study there is **always** a threat of suicide, but public concern has focused overwhelmingly on the risk that psychiatric patients present to the public.

Threats, Swearing and Overdoses

“They’d be better off dead those schizophrenics, be better if they killed themselves. It would put them out of their misery, otherwise they just go and hurt innocent people” (woman after the sentencing of man with schizophrenia who killed a school girl in Cleveland).

This section will focus on two areas of behaviour that are heavily influential in the lives of carers of adults with severe mental illness. Not all of the study group spoke of such experiences, but many did and did so quite spontaneously. For a significant minority experiences including self harm, verbal and / or physical aggression were so commonplace that individual incidents were difficult to recall (it could also be suggested that a healthy dose of amnesia acted as a valuable coping mechanism). Verbal, and physical, aggression can be viewed as a part of everyday life, with family violence permeating all social layers. Such aggression is not considered socially desirable, and respondents are likely to feel uncomfortable about identifying it. Although aggression by someone who is mentally ill can be put down to illness rather than personality, carers are still likely to feel disloyal when highlighting its presence. Carers may also be reluctant to reinforce the stereotypical image of the *mad* person. In 1996 the media image of someone suffering paranoid schizophrenia is that they are armed with an arsenal of knives and lie in wait for unsuspecting members of the public.

The Media and the Mentally Ill

At the present time public concern focuses predominantly on the risk that such mental patients present to 'ordinary' people. Cases of discharged ex-patients diagnosed with schizophrenia who kill, attack, rape or generally run wild attacking everyone in their path are regular news items. Indeed the term 'schizophrenia' has become (even more) pejorative, indicating that the owner is likely to develop a homicidal rage at any time. Manic depression, once the diagnosis of the eccentric, creative genius is also under threat, and a 1995 edition of the television science fiction programme 'The X Files', included someone with 'a bipolar disorder', lying in wait for the heroes armed with knives (there seems to be a particular emphasis on knives).

There are two common reactions to the media construction of mental illness as homicidal madness. Firstly, that it is *the truth* and everyone's safety is under threat because such people are no longer kept under strict supervision in hospitals, and secondly that it is unjust discrimination borne of fear. Mike Lawson, user and writer, remarks that "statistically you are safer with a mental patient than anyone else".

Media Images

Stories concerning the violent activities of *schizophrenics* discharged inappropriately to the community have featured regularly in the press. I will quote a small sample, providing a flavour of the articles. Perhaps the most famous incident was the death of John Zito, who was stabbed by a black man suffering schizophrenia in 1993. John was standing on a London tube station, he did not know Christopher Clunis who had been in and out of psychiatric hospitals yet had never been offered continuity of professional support (Ritchie, 1994). John's wife, Jane Zito, has become a familiar face in both the press, and in professional publications. Her trust, which supports families of people killed or injured by mental patients, advocates secure care for a small percentage of patients who, in its opinion, are dangerous to the public.

The government Mental Health Task Force, now disbanded, also criticised community care. The Times reported that 'patients with severe mental illness were being discharged too early from London hospitals because of bed shortages, and that many posed a threat to their own and public safety' (Hunt, 1994:7).

The Mail's comments, in 1995, were rather more lurid. In discussing what professionals might call assertive outreach, it talked of the consideration of plans for 'mental health hit squads' which would 'scour the streets for dangerous schizophrenics' (Eastham, 1995:12). Such ex-patients are said to lose contact with medical and social services. Living rough and without medication, they put others (normal people) at risk. The article is interspersed with examples of murders carried out by other schizophrenics (sic).

Bale (1995:3) comments in the Times on the non-fatal stabbing of a GP in London. Although a diagnosis is not given, it is stressed that the culprit had recently been discharged from psychiatric hospital and that the policy of community care was a failure.

The Newcastle upon Tyne Journal (Murphy, 1996:7) carried the title 'ex-mental patient in knife horror attacks' and refers to a patient's vendetta against women. There is a large photograph of David Morgan, a black man, and a statement about his 'grudge' against women. David, also said to suffer schizophrenia, slashed the throats of fifteen women shoppers in a large city.

As I write, in February 1996, the debate continues with the suggestion that courts are increasingly unprepared to trust psychiatrists with the care of severely mentally ill people who are violent, and will sentence them to prison, rather than to a period of treatment (Midgley, 1996:3).

The message in the media is very clear and portrays the 'schizophrenic' as pitiful but demonic, and always ready to attack innocent bystanders. The

government has even seen fit to issue a charter that assures patients (and everyone else) that they will not be discharged from hospital if there is any risk of harm to themselves, others, or any formal, or informal carers (there is no discussion of resources in this charter).

Families and Aggression

Somewhere between the two positions, ie. that severely mentally ill people are violent, or that they are peaceful, frightened, retiring individuals, one may reach an understanding which will inform provision to support and protect both mentally ill people and those in contact with them.

Are the severely mentally ill more likely to attack someone (with knives?) than anyone else? These stories prey on public fear of insanity. In some sense aggression by mentally ill people may be perceived as more threatening because it can appear unintelligible. The public may feel more able to accept (and empathise) with aggression by thieves or betrayed marital partners, but not the seemingly erratic, unreasonable acts of violence committed in response to delusional thinking that are associated with insanity.

For carers this tension can feel shameful. It must be concealed, even from others in their family, and leaves carers exposed and isolated. It would have been easier if carers could have proudly asserted that they had never experienced aggression in connection with their relative's problems but around half the group had witnessed acts of aggression or threats in connection with their relatives mental ill health.

Aggression and Carers' Experiences

It could be argued that once labelled as sick, the user's behaviour is subject to scrutiny and more likely to be pathologised by other members of the family but this did not appear to be the case. Carers were concerned about incidents that were felt to be outside the bounds of normality and beyond what they had ever expected to encounter given their previous relationship with the user.

Mrs AA's mother had often hit her husband and other members of the family over the years. This aggression was associated with periods when she was 'unwell' and was not a normal feature of her behaviour. The family were accustomed to this problem but on one occasion her husband hit her back. Mrs AA said her father could never forgive himself, and insisted that they live apart, but he continued to support his wife, seeing her most days.

Mrs W's son had called one evening and had argued with his parents. When they returned later that night, after going out, they found a fire engine at the door. He explained that he was annoyed with them and had burned the living room down. The damage was extensive.

Mrs V's daughter could be particularly unpleasant when upset, and would suddenly lash out. She had hit her mother on many occasions on the head in the car, and had bent her mother's fingers right back. There was little or no external reason apparent for her outbursts.

Some carers had to hide incidents from others in the family. Mrs Q explained that if her husband knew she had been hit by their son, he would "stop me from going". Carers in such circumstances had to indulge in an elaborate facade hiding their emotions at a time when they needed support. Other adult children were often scathing, demanding that the carer cut the patient off as they did not deserve help. Carers inevitably felt torn. A worrying dimension to Mrs Q's and similar cases was that professionals often appeared inept at intervening with the CPN making the excuse that he could never gain access to her son, who would not wait at home for their appointments. This reinforces the impression that it was the most disturbed, confused, sick, and disorganised patients who were the least likely to maintain contact with professionals. In this particular case care and monitoring was provided only by the mother, she in turn received no help in this role whatsoever.

Other users were not actually violent, but said odd things that frightened their families. Mrs X's son looked deep into her eyes and said that he was going to take her "to heaven" with him. She made a rapid exit to phone for the doctor. Greer and Wing (1980:50) accurately describe the sensation as living next to a 'volcano'. Aggressive outbursts could follow arguments or frustrating experiences, but they also occurred right out of the blue and it was impossible for carers to anticipate them.

This could lead to a great deal of tension. Carers found that their relative could become increasingly unwelcome at social gatherings and that people did not call at the house.

The 'best' place for aggressive incidents to occur was in hospital where the behaviour could be concealed (and more easily forgotten). There were staff on hand and easy access to medication. Unfortunately, carers could not rely on their relatives to be in hospital at the appropriate time, nor could the hospital be relied on to retain angry, indignant (sick!) patients who were potentially unmanageable at home, but who refused to stay in hospital. Informally, carers in the current study have NVQ'ed in what might be euphemistically called acute or special care nursing in their own homes.

Compulsory Care

During times when their relative was aggressive the carers looked to professionals 'to do something', and to use their compulsory powers under the 1983 Mental Health Act. Carers often complained that even though their relative was, in their opinion, sick, disturbed, and impossible to deal with, professionals appeared paralysed and hesitated to act. Carers wanted a decisive, rapid response. As one carer said, "wham, bham, and they're in". Any failure to provide protection was met with anger, despondency, and sadness. Carers repeatedly stressed their disbelief that nothing could be done.

Carers described a familiar pattern of deterioration and the gap before their relative's mental state was considered severe enough to merit admission under a section of the Mental Health Act 1983. Mrs M explained, "He was out of hospital another year and then went downhill again. The social worker didn't feel he was sectionable but thought he might be in a couple of days. They tried to get him into a hostel but he punched our mother and broke her cheek bone first. They still didn't feel he was sectionable and he had to hit rock bottom before they did it." Mrs M added that when her brother "is left too long it takes longer to put him right".

While professionals wait until the user is sectionable the carer must try to cope with deteriorating behaviour and relationships. I quote at length from my research diary. The extract was written immediately after my partner had been taken to see his consultant following a row with a neighbour.

I don't know which is worse, the mania or the depression. When they are depressed you can, if you still possess the patience, comfort them and promise them hope. The manic phase starts insidiously and is impossible, at least in our case, to distinguish from tensions that normally occur in relationships. At first I am confused and then aware that I am living with someone who feels like a time bomb, waiting to explode. In order to try and exert some control I perform emotional and verbal manoeuvres that make me feel like a limbo dancer.

The psychiatrist says I am like the thought police. Whose task is it to spot the changes? I am forced again and again to accept responsibility and I cannot ignore them when they exert their presence through our relationship. Anyway, they didn't notice. He went to the mental health group to insult people and came away realising he was full of rage and might be high. He told the CPN

who felt it wasn't significant. The surgery had said that his lithium level was 'fine' when it was below therapeutic levels.

I felt cheerful yesterday. He seemed less volatile and all my catastrophising about scenes, ambulances and sections alarmist. I keep asking myself if I overreacted, I'll never know. They are never there, I am. The kids shouldn't smash our flowers with their ball but he erupted. We have never had problems like this before. He was going hammer and tongs with two neighbours and I got in-between and separated them.

I went and found the staff and volunteers at the mental health coffee morning and cried hysterically. He was unrepentant and full of abuse. The nurse organised an emergency appointment with the consultant. The psychiatrist dished out a new form of anti-manic tablet and felt that apart from 'manic irritability' my husband was definitely better. He was much calmer now but I was despondent.

I feel flat and empty and that all my achievements are dust. I am burnt out, exhausted and demoralised. I think I really needed a rest and at the time didn't want him back, at least not immediately, but I wasn't asked. It was blithely suggested that I go somewhere for a break. Where for God's sake?

(Personal Caring Diary, June 1995)

I was told that I was overreacting, my partner insisted that it was "an ordinary row with a neighbour". None of the professionals present, CPN or ASW, talked to me about my fears nor supported me. It was assumed that I should take him back home and carry on, or that we might need a break, a few days apart. The CPN later told me that he was well aware that my partner was manic. My

husband, being ill, had no insight, and did not feel his behaviour was extreme. I was left utterly isolated to manage an ugly, threatening situation.

This incident needed to be viewed in context. My partner had described feelings of being out of control for a couple of weeks. He told me that if provoked, he might lose control completely and run wild. Suspecting a manic episode, he even had his lithium level checked. He was told it was normal but it was actually too low. If professionals had listened to his and my concerns the very damaging outburst need not have occurred. Acquaintances, even close friends and family, are rarely prepared to give the user a second chance and often withdraw from involvement. At these times the user often lacks insight and depends totally on the carer to protect them and prevent them from acting unwisely. This may mean depriving the user of their liberty but unsavoury as this is, it can be necessary. Practice in connection with compulsory admission appeared widely variable. It seemed that once a carer was known (and after a number of crises) professionals might be more prepared to accept their carer's opinion. There are clear problems inherent in the situation. The user could be vulnerable to malicious or just over-zealous attempts by their carer to control their supposed illness. Once labelled, all problems could be conveniently viewed as a result of the user's symptoms. Given this real danger, professionals must proceed with caution, but evidence in the current study suggested a reluctance to use statutory powers until the situation had become extreme (and not even then). As one mother said, "they say he has rights but what about my rights? I have none".

Verbal Aggression

Associated with physical violence was the presence of verbal aggression and when users were unwell this was a common feature. Users seemed to say things that were extreme or totally out of character. Carers became accustomed to being sworn at and generally insulted. Other users became loud, demanding and overpowering.

Professionals might dismiss such outbursts as normal and remark that many people conduct themselves in that way most of the time. Carers were often cut to the bone by cruel comments. If other people overheard, it reinforced their image of the user as a thoroughly nasty person, undeserving of any support.

Inanimate objects also suffered abuse: doors and cars were kicked. As previously mentioned, carers tried to believe that it was their relative's illness but it could be hard to do this. Professionals did not help, but fluctuated from telling carers that the patient was ill and could not help themselves on some occasions, and on others to suggesting that the user was simply behaving badly. I too continually underwent this process. Could my partner help it when he was so irritable and demanding with nurses, or was he high and out of control? He did not know himself. We have discussed this issue at length and conclude that a dichotomy is unhelpful. My partner explained that there were occasions when he could observe his behaviour and felt appalled by it, but could not actually control it. Carers and users need help to develop strategies to maximise self control and to diffuse situations. Such strategies must be given outside of a judgemental, condemnatory framework.

A Model for Understanding Scenes

Aggressive behaviour and communication is recognised in the literature though advice for families is often trite. Spaniol notes that 'bizarre and abnormal behaviour is another major concern of families. The most commonly reported strategy is to sit down and talk calmly with the disabled family member' (Spaniol, 1987:215).

A 26-year old woman suffered from recurrent manic psychoses that responded to anti-psychotics and lithium carbonate, but she remained short tempered even on the medications. When stressed she would break objects in the home. After various trials of medications to improve the patient's temperament, her psychiatrist advised the family that no further behavioural improvement could be achieved with medications.

With the help of a family counsellor, the family developed a set of clear expectations and limits for the patient (Spaniol, 1987:121).

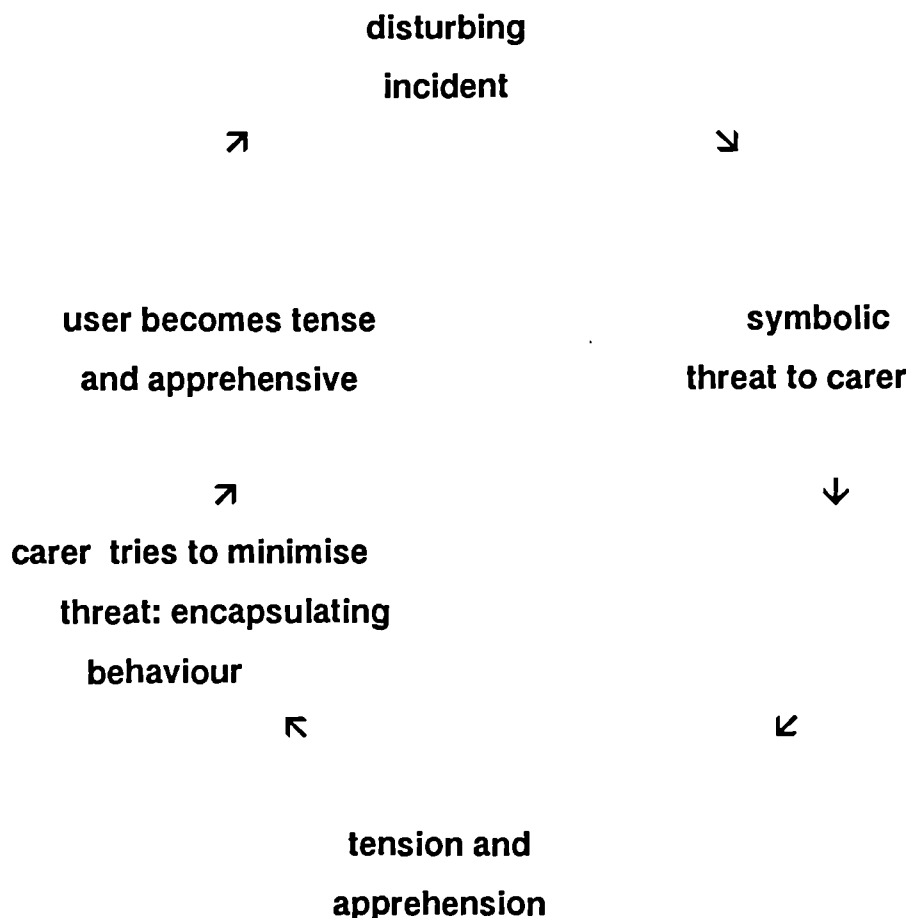
This type of behavioural contracting was not mentioned by anyone in the study. Carers faced with ongoing disturbed behaviour felt they had to either accept the behaviour or make their relative leave home. Many felt uneasy about the latter option as it seemed probable that the user would not be able to cope. Literature also suggests that emergency help and hospital care may be the most appropriate way of caring for a disturbed individual but this position does not acknowledge the reality that carers face. Where there are severe bed shortages, pressure on community based staff, and where professionals fail to recognise the impact of aggression and disturbed behaviour, carers can expect little comfort. Kuipers et al advise professionals to remain calm when discussing disturbed behaviour with families and to be careful not to take sides (Kuipers et al, 1992:43). The suggestion about impartiality appears to derive from the systemic approach discussed earlier in the thesis. The therapist is detached, impartial, and views difficulties as being located within the system. Admirable as their position may be (I am not advocating the scapegoating of the patient) there is a need to empathise with the carer, who is likely to feel vulnerable and unsupported.

Left without help there can be little doubt that the situation can deteriorate through an uncontrolled spiral of tension. Carers may react with apprehension to an aggressive, bizarre, or disturbed comment or action. This fear occurs within a symbolic context. Professionals may argue that 'nothing much happened' but carers are likely to view the threats or cruel comments as a violation of their emotional and physical safety. Their home, their relationship, their future happiness are all under threat. These fears are likely to intensify the carer's reactions to their relative and they can become inappropriately tense or resort to being critical, and are more likely to overreact in the face of provocation. Carers will also feel a need to indulge in a form of 'encapsulation'. Given that outsiders view displays of odd, irritable, and disturbed behaviour

with disapproval, carers will attempt to cover up for their relative. Encapsulation includes avoiding situations which might provoke the relative, intervening, or encouraging the relative to withdraw from confrontation with other people. Carers explained that doing routine tasks such as shopping, eating out, going away, waiting for an appointment or just having someone call at the house required vigilance on the carer's part. It is not so much what the user does as, given past experience, what they *might* do.

The situation when a user is agitated, obsessive, or tense can only be aggravated if the carer reacts by becoming increasingly uneasy. The carer's tension, hostility, or impatience is likely to result in a further deterioration in the user's mental state.

This vicious circle can be shown as below.



Research on the link between high expressed emotion in family carers of people with schizophrenia illustrates the importance of maintaining a calm, supportive, and non threatening home environment. Carers may well recognise that they are becoming inappropriately anxious and that this can only have a negative effect on their relative. This does not, however, make it any easier to control such feelings. Carers are too often expected to 'work' twenty four hour solo shifts in the presence of tension. Lacking respite from such pressure, it is not surprising that they feel unsupported. Given the cycle of disturbing behaviour and apprehension by the carer, professionals need to intervene at an early point, before patients hit rock bottom and the carer's capacity to cope is exhausted. A failure to do this has negative effects for the user and may stretch the carer to a point where they feel that they are not prepared to continue to offer support.

Helplessness

Attempts to understand the genesis of depression have covered a variety of agents and these include an inability to control adverse events in one's environment. Engel has referred to helplessness where the individual feels let down and in a situation where they can do nothing to control it (Gelder et al, 1993:410). Brown and Harris have described the feelings of hopelessness that arise in the context of adverse life events and inadequate social support.

Recognition that loss plays an important role in depression has, of course, been widespread. While a good deal of the extensive research literature has dealt with death, Freud made the point in *Mourning and Melancholia* that the object need not necessarily have died but simply have been lost as an object of love. The way in which we have categorised events follows a similar line of thought. Basically we have seen loss events as the deprivation of sources of value or reward. We now go further to suggest that what is important about such loss for the

genesis of depression is that it leads to an ability to hold good thoughts about, our lives, and those close to us (Brown and Harris, 1984:233).

Carers can easily be described as helpless and hopeless. They can face a prolonged period of uncertainty where they are regularly confronted with the possibility of disturbed or abusive behaviour. They feel there is often little they can do to control the situation. Carers may reach a position of helplessness where they feel threatened at any moment in time. It is not surprising that many carers succumb to clinical depression given the destructive impact that these experiences can have on their ability to retain optimism. If one accepts this model its implications are clear. Professionals should recognise the carer's vulnerability in the face of ongoing exposure to unpredictability and should make every effort to alleviate this, using early admission to hospital, or respite care if community support is inadequate.

Self Harm

The government has placed particular emphasis on the need to reduce the suicide rate in its Health of the Nation proposals. Not only the global rate, but particularly that of the chronically, severely mentally ill (some 10 to 15% of this population commit suicide). Nothing is said about how this is to be achieved. Much is written about suicide, both sociologically, epidemiologically, and clinically. My focus, however, is on suicide and self harm as it affects carers.

The confidential inquiry into homicides and suicides by mentally ill people asks readers to recognise the individuality of each case and states that

In this report we can offer no universal remedy that would have prevented the individual personal tragedies reported to us. Each of them was a distinct event, often unexpected, and seldom resulting for a dramatic breakdown in arrangements for psychiatric care. It is unrealistic to expect that every homicide or suicide is preventable. This inquiry acknowledges that, even where psychiatric care has been

comprehensive, situations will arise which are beyond the control of the supervising professionals (Boyd, 1996:64).

Caring relatives do not have the wider perspective that is the privilege of professionals. They are concerned with the well being of *their* relative and can not avoid the feelings of guilt, when things go wrong, and helplessness, in case they might. Unlike violence, self harm is not regularly featured in the media, and the public lacks the sense of concern that is attached to aggression. Although self harm and homicide or violent behaviour appear to be associated with the same categories of mental illness (Boyd, 1996), it is far more common for mentally ill people to harm themselves rather than other people. Boyd's report reviewed incidents between 1992 and 1993. They examined home office files and located 39 cases of homicide between July 1992 to December 1993, and September 1994 to March 1995. 240 suicides were noted between June 1993 and December 1994 (Boyd, 1996:8).

Greer and Wing's 1974 (Greer and Wing, 1980) study of members of the National Schizophrenia Fellowship demonstrated that actual suicide, suicidal thoughts, threats, and acts of self harm were a familiar feature of the illness for many carers. They noted that "some mention of suicide was not uncommon". About one quarter of all the patients had said something about it during the previous year. Sixteen had made an attempt at some earlier time and three had made serious suicide attempts during the year (Greer and Wing, 1980:31).

Of the group that I studied, one man killed himself some months after I had talked to his mother, another woman with whom I had worked killed herself some weeks before I commenced interviewing, and most of the remainder had contemplated suicide or had attempted it at some point. There was another type of behaviour associated with this area though not obviously suicidal. Many users had cut themselves at times of anguish or had harmed their bodies in other ways. Like violent behaviour, self harm has the effect of breaking down any semblance of safety that the carer has nurtured about their family's

situation. It can engender a perpetual insecurity. The examples from the current study are chosen to be representative not sensational. As discussed earlier, in some cases the relative's first tangible symptom was to be severely suicidal. Although an early attempt was perceived in dramatic terms these experiences became regular events for many carers who live from crisis to crisis. In this sense the carer's journey often felt cyclical and this engendered a particular hopelessness.

Mrs O's son had appeared quite relaxed but had actually taken an overdose of tablets. She worried continually about "finding him" again and about not being able to cope. (It was her son's psychiatrist who had insensitively joked about his attempt to kill himself by bridge jumping only one week later).

When Mrs M's mother was the carer for her son there had been numerous occasions when he had "taken tablets". Her mother "would walk him up and down to keep him conscious until the ambulance came".

Self harm was often an expression of utter desperation on the user's part. Mrs X's son had cut his testicle and an eye on separate occasions.

What these descriptions fail to do is to convey the horror that carers regularly confront. This takes a toll on their will to carry on. In my partner's case it is difficult to quote any one example of suicidal behaviour that can reflect adequately our experiences. Thoughts of self harm could alternate rapidly with anger or sheer terror. The most demoralising aspect was the inability to perceive any future respite from the distress. In many ways it was easier at the beginning, one could legitimately promise hope, even a cure, but as time went on the suffering continued with only very brief periods of relief. He would cry and tell me that, "it will get me eventually". Like a vulture circling above a wounded animal, it sits and waits for the inevitable opportunity.

I live very close to death, when I look in the graveyard near our house I wonder what I would tell them, would anyone understand how hard he had fought, or would they see it as a fitting end to a worthless existence? At times one feels tired and unable to fight any longer. Then the sneaking thoughts come, perhaps I should just let him go. I am torn between selfishly wanting an end to my own fight on his behalf, and wondering whether it is actually selfish to force him to live in pain for my sake (Personal Caring Diary, February 1996).

And, when one of them “does do it” and actually commits suicide, it affects us all: carers, users, and professionals. Professionals, especially those providing crisis-orientated work, may become desensitised to the impact of actual or threatened self harm. This is apparent in Mitchell’s work on “dealing with mad clients”. In examining situations involving severe mental distress he looks at the response of social workers who provide out of hours services - the emergency duty team. One social worker used the term ‘furore’ (Mitchell, 1993:87) to describe a crisis associated with a ‘regular’ client. Crises did not seem to differ significantly from a furore, but it ‘differs in that what is occurring is not new. Rather than being a fresh incident it is a repetition of a previously unresolved crisis’ (Mitchell, 1993: 87-8). He adds that social workers have lower expectations for such clients and are also reluctant to expend too much energy on resolving the situation.

It was more of a furore. A chronic patient acting up again in a way to get herself admitted. This meant that I was less committed to work it as a crisis case. I was not concerned about the outcome. It just didn’t seem worth putting lots of effort into a well known patient acting out again (Mitchell, 1993:88).

Mitchell recognises that this way of conceptualising people in crisis could 'become another 'labelling' word which in turn may help create the very 'stereotype response' that is purports to describe. The implication of the above is that something new or different needs to be happening for the case to be considered a crisis (1993:88).

For carers whose relatives either fail to respond to treatment, or who do not comply with the medication offered, there can be repeated crises but there is an unspoken assumption that users are entitled to a fixed amount of attention from professionals. A couple of night calls from the GP, one or two emergency admissions to hospital but that thereafter they should show some response. Failure to recover after having been awarded the appropriate care, is tentatively assumed to be culpable. From this position professionals may become suspicious and suggest that the patient is malingering or that in psychiatric terms, they have a personality problem. Social workers are no less generous in their judgements. A failure to present for help on the carer or user's behalf, may not indicate that there has been a recovery, or that the family has at last employed its own coping strategies. It may simply mean that the family feel that there is no point in telling anyone anymore.

Crises associated with suicidal gestures, acts, and ideas are an integral feature of life for the user and anyone close to them. Given the length of time the symptoms may persist, carers and professionals who remain committed to the support of people vulnerable to suicide will need support in their own right. Suicide is not usually associated with psychosis but is often contemplated in the intervening periods when the user may take stock of their life or may occur during the depression that often follows an acute episode (Carr, 1993:2). There is also strong evidence to show that people recently discharged from hospital are particularly vulnerable. An Oxford study found the suicide rate to be 213 times the average for men and 134 times for women, during the first month after discharge (Carr, 1993:2). This suggests a *need* for intensive community support and for consideration to be given to the quality of life and future prospects for people diagnosed as severely mentally ill. The decision

by many to kill themselves can be regarded not as insane, but logical given their circumstances. Many professionals, at least in private will acknowledge that the lives of chronically, severely mentally ill people are desolate.

Chapter Eight

Redefining Carers' Experience and Need

The final chapter of this thesis will attempt to draw on the data from the current research in order to form a theoretical account of the experience of carers. It is vital to treat the study findings as tentative given the limited scale of the sample size. However, there would appear to be useful lessons to be learned, if only in the sense that the findings may lead to a reappraisal of professional practice in relation to carers of severely mentally ill people.

Initially I will examine the evidence for supporting the conceptualisation of caring as 'loss'. The ways in which professionals understand the behaviour and feelings of family and informal carers undoubtedly mould their responses. Reconceptualising the experience of carers should therefore be reflected in changes in practice. These changes could demonstrate a commitment to moving towards a greater partnership between professionals, service users, and their carers. This partnership is the corner stone of policy rhetoric and is reiterated in the recent Green Paper 'Developing Partnerships in Mental Health' (Department of Health, 1997).

carers and professionals

In analysing data from the current study, one is dismayed by the predominance of negative experiences recounted by carers in connection with mental health services. (Where at all possible positive comments and outcomes have been reported). The sample was selected to reflect a broad spectrum of user and carer characteristics and were not merely disaffected members of local action groups. Perhaps it is not surprising that so many users and their families appeared angry, for it must be stated that severe mental illness is often a very harrowing experience and frequently leads to some degree of prolonged suffering. However, there did appear to be some problems in the *responses* that carers encountered. They often indicated that their painful situations might have been eased if professionals had responded differently. It is therefore the task of this research to provide a voice for these carers and to consider whether it might be possible to modify practice accordingly.

In reviewing the thesis in April 1997 I am aware of a certain vehemence in my comments about the reluctance of professionals to 'listen' to carers. Having asked a small number of carers to read and comment on the draft thesis they felt readily able to endorse such a stance. As the author of the account, the demands of reflexivity require that I examine my own experience and role in the creation of the data. My personal stance mirrored that of many of the study subjects. They were frequently angered by their encounters with the system, which they felt failed to respond to their reasonable requests for help. I had very similar experiences, and it is only now, given the luxury of my partner's recovery, that I can observe the extent of my anger. However, it would be very wrong to ignore the weight of feelings that subjects expressed. Much can be learned from this, and cynically I can observe that it is easy to forget the feelings of frustration and abandonment when one is no longer encountering self harm and violence daily.

Throughout the study I sought patterns that I could interpret and record as the basis of theoretical models. I began to realise that the time scales that were involved made the recognition of any patterns very difficult. While the course of bereavement runs from death or a loss, which is usually a discrete event, the process of living with mental illhealth is complex. Often, having no clear boundaries at the time of diagnosis, the user and carer have frequently been struggling with their difficulties for months if not years. Some carers in the current study had had no formal diagnosis, but were encountering problems identical to those whose relatives were considered to have a severe mental illness.

Recognising Relapse and Professional Deafness

As previously discussed, the possession of a diagnosis and allied information could be a mixed blessing. It might provide an explanation, could be a passport to services, but also entailed stigma, pessimism, and veiled messages of personal decrepitude. Such messages radiated throughout the life of the whole family and exacerbated feelings of guilt and dismay. Handa (unpublished) observed that stigma may be more intense in some ethnic minorities. The caring experience is often cyclical and the recognition of this can make carers feel utterly helpless. Many carers felt condemned to watching symptoms develop, struggling to make professionals accept that there was something wrong, enduring the pain of their relative's anger and their humiliation in hospital, and then feeling hope and elation at recovery, only to

watch as the seeds of the 'parasite' germinated all over again. This cycle of suffering could be observed repeating itself through the lives of so many of the users and carers that I encountered. Literature is ripe with suggestions that professionals teach users and family carers to recognise relapse 'prodromes' (Huckle 1993:12) but the data suggests that practice may be unprepared to assist carers in raising such concerns. Carers in the study explained that they can recognise familiar themes that signal all is not well. "He always puts his things away, it's his way of saying he is not worthy enough to have them". "He shouts at me and accuses me of things in a way that he never normally does. Then I know, it has started again". The cyclical nature of relapse and recovery finds professional recognition through the concept of the 'revolving door patient'. This process is disheartening for professionals as it engenders feelings of failure, but it is more depressing still for the user and their family.

This particularly unpleasant phase in the cycle where the carer recognised symptoms of relapse could often lead to conflict with the user. Was the carer over-analysing every move their relative made searching for tell tale signs of psychopathology, or were they just being sensitive to subtle changes in behaviour which go unnoticed by professionals? For many carers this process was a familiar and painful aspect of their role, and a source of resentment against professionals, who they felt were virtually negligent in their refusal to listen and act upon the carer's concerns. It caused a significant number of carers in the current study to harbour bitterness towards professionals, which it may be argued might have a detrimental influence on the ability for carers and professionals to work together for the user's benefit. In her ongoing research Janice Hutt (another northern carer-researcher), (Hutt, unpublished), has also observed the frustration and distress caused to carers when they feel their observations are not merely dismissed and ignored, but actively resented. Some carers complained that alerting professionals had led to professional concern over the *their* mental health. Hutt's research and the current study reveal anger and despair at this process. (Carers who had not experienced difficulties in this area were those whose relatives possessed so-called insight and would seek medical advice on their own behalf. In relation to psychotic disorders such insight is usually relatively uncommon). Carers were angered by these problems as they believed that an early recognition of relapse could prevent their relative deteriorating and might avoid admission under the Mental Health Act.

Perhaps such responses might have been understandable, especially in the early phases of receiving 'help'. (It would be all too easy for a distressed 'carer' to scape-goat a relative, deluding themselves that someone who will not accede to their wishes must be mentally ill). Unfortunately the errors in relapse recognition appeared to be made repeatedly. Recourse to experience, and to any previous medical history, did not prevent the process repeating itself. Some carers argued that it was only after a tragedy that professionals listened.

The Obstacles to Partnership

Many carers felt actively resented by many professionals, they rarely ever spoke of partnership. There were some exceptions, in particular a few sensitive words seemed to make an enormous difference and carers remembered such comments even when the professionals were unable to effect any positive outcome.

The reasons for the antipathy that professionals may have demonstrated towards carers is difficult to interpret. (If carers are free, willing participants providing twenty-four hour care, and even risk assessment, one would think they would be supported fully). I have come to suspect that carers of people with mental health problems may be mistrusted because they break societal norms concerning adult autonomy. Society accepts the dependence of children, and that of older people (who are represented as being unable to make decisions for themselves because of perceived physical and intellectual frailty). People with mental health problems, however, are seen as being different, they often appear (and are) fully independent, but at other times they can be unpredictable, dependent, and allegedly dangerous. Professionals may, in the eyes of carers, become paralysed, through inappropriate concern over confidentiality and self determination. However, professionals are charged with the task of protecting vulnerable people from exploitation, and the line between inappropriate intervention and neglect is notoriously narrow as experience in child protection issues has demonstrated. Social workers are trained to be aware of the disempowerment of mentally ill people and seek to defend their freedom, despite carrying authority to detain patients in hospital.

By default the onerous task of making impossible judgements may have been passed to family carers. Perhaps society needs carers to support vulnerable people and prevent them from harming themselves or falling into self neglect.

It also increasingly seeks protection from potential aggression, and requires that bizarre behaviour be concealed- hidden from public view.

The role played by carers of mentally ill people is increasingly a necessity given the retraction of state care but it may be morally unpalatable. Professionals may harbour thinly veiled distaste at carers who appear to 'betray' their own family members. Carers alert others to signs of an illness, which many people still believe to be a failure of moral fibre, an 'illness' of which the 'patient' is often totally unaware. At present ethical codes and legislation seem ill-equipped to meet the complexities involved, and a situation has developed where family carers act as emotional barometers in the care of mentally ill people. I frequently felt repulsed and trapped by the responsibilities that I had acquired but believed that if I did not perform the monitoring role my partner might harm himself or someone else and suffer the consequences. This sentiment has been expressed by Devenson who quotes a Canadian mother whose son suffers schizophrenia.

We are the parents of the throwaway schizophrenics, the disposables, the ones who are the most difficult to treat; who are often, as a result of their disability, unable to ask for or accept help. They refuse it. Left without treatment they continue to suffer. Relatives must stand by and watch, unable to alleviate the suffering which is in the main ignored by the mental health system until it is sometimes too late. It seems to be the same story the world over. We are the people who are told that you can't help those who won't help themselves, and we reply under our breath that you won't help those who can't help themselves.
(Devenson, 1992: 244)

There will be a further discussion of the implications of these observations in the recommendations for practice later in this chapter.

Caring and Loss

Several people in the current study endorsed their experience as a 'bereavement' without prompting, others felt the expression described their situation when offered the term, but they lacked the vantage point gained from contact with other carers over a prolonged period. I also had the opportunity to observe and reflect on my own caring experience and it was then that a more

complex pattern became apparent. The data suggested that the concept of *attachment violation* might provide a more appropriate description of the experiences of carers of mentally ill people. Carers involved in reviewing the draft thesis recognised themselves in the terms that have been adopted.

Surprising little attempt has been made to conceptualise the experience of family carers of people with severe mental illhealth. Where discussion does take place there is often some comparison made with bereavement. This approach is typified by the handbook written for professionals working in this area, where Kuipers et al suggest that family may need assistance in order to deal with their feelings of *loss* (1992:55). They talk of the need for carers to reduce their expectations for the person, and advocate encouraging acceptance and adaptation. Other texts focus predominantly on the reduction of high expressed emotion, indeed Atkinson and Coia (1995:197) advise professionals to beware of situations where carers 'become very upset'. The idea of applying loss theory to this area was superficially very promising. It would seem to offer a ready-made theoretical framework which could enhance understanding and improve professional practice. At the outset of the current study my professional contact with families supported this model, and the research set out to explore the degree to which loss theory could be used in this way.

The conceptualisation of carers' experiences requires an examination of bereavement theory and in particular loss. I will explore the ways in which it has been defined and examine data from the current study through its parameters.

Bereavement

There is a wealth of literature which explores the phenomena of death, grief and mourning. It is closely associated with theory concerning symbolic death ie. loss. Machin notes that death and loss are closely associated with change (1994:1) but that they lack the positive features that are present in other forms of change. 'In some forms of change we have no choice- physical ageing- but in others we make choices in the hope of improving our situation' (Machin, 1994:1). Loss or death may be aggravated by trauma where the loss has been sudden, untimely, or inappropriate. Hence the death of a young child or the loss of one's health in the first half of life can be seen as unjust.

Grief is conceptualised, not as an event but as a journey, through which in Freud's terms, 'each one of the memories that bound the bereaved to the deceased is brought up and then painfully relinquished' in (Raphael, 1984:44). One may add that not only are memories implicated in this process but also all one's hopes for the future. Theory on the content and course of mourning makes reference to a number of *stages* in the grieving process. Machin suggests that grief is better regarded as a 'struggle' in which the release from pain may be achieved either by evasion or confrontation' (Machin, 1994:4). In brief, when faced with a profound loss the individual is confronted with making a painful adjustment. This will entail the difficult process of disentangling one's hopes, interests, perhaps one's whole inner and outer world from its familiar resting place, and, gradually, as the wounds heal over, finding the courage to reinvest this energy elsewhere.

Writers appear to agree about the stages said to occur. These are given as:

- Numbness and denial
- Yearning or searching for the lost loved one
- Disorganisation and despair
- Reintegration and reinvestment

(Bowlby, 1986:85), (Machin, 1994:4-5)

Kubler-Ross adds a further stage characterised by hope (1969:123).

Bereavement theorists and professionals working in this area have developed a specific therapeutic approach which can be recognised under the generic category of bereavement counselling. People who have suffered the death of someone close are considered to benefit from assistance in passing through these stages. The voluntary agency Cruse exists specifically to offer bereavement counselling.

Worden explains the purpose of grief counselling as helping the bereaved person to pass through the necessary stage successfully. Counselling is believed to achieve a number of tasks which include: increasing the reality of death (ie. preventing denial); allowing the individual to express their feelings and deal with any 'unfinished business'; and, finally, to permit the individual to feel able to reinvest in life having put their loss behind them (Worden, 1995:38).

Loss Theory Applied to Other Experience

Loss theory has increasingly been used to conceptualise and inform practice in a wide range of areas. This process requires evaluation because it is easy to recognise the similarities between experiences and ignore the subtle but fundamental differences. Loss theory has been used to understand the experience attached to divorce and the ending of partnerships. Raphael applies the concept to divorce but comments that as divorced people often vilify their ex partner, rather than idolise them as some whose partners have died do, there is an added potential for guilt (Raphael, 1984:228). Rickford notes that ageing, though a normal process, entails frequent loss which may include the loss of mobility, hearing, health, and just the understanding that you are 'deteriorating' (Rickford, 1996:17). Lascelles extends the list to include redundancy, mastectomy, colostomy, miscarriage, having a child received into care, and the loss of a limb (1985:35-50). It is not difficult to see the justification for their approach, and there is empirical evidence to support the idea that the emotions and behaviour of people facing these events are similar to those experienced by people who have suffered loss through bereavement.

Not surprisingly there is a growing literature about the impact of the HIV virus and the problems faced by people caring for those with the full syndrome. As with schizophrenia so many of the people who have become terminally ill are young and this challenges our hope for the future and our sense of what is fair. Many gay men have had to face multiple bereavements through losing partners and friends. Although there is more optimism and talk of drug cocktails that may slow or entirely prevent the full syndrome developing, some have been faced with caring for a young person with a very debilitating combination of symptoms, ending in death. A study of white gay men in the USA found that carers who had lost a partner or close friend had symptoms akin to post traumatic stress disorder (King, 1993:145).

Loss and Alzheimer's Disease

The carers of people with dementia interviewed in the current study readily endorsed the idea that they had experienced a *bereavement*. This applied to the woman who cared for her husband over ten years, up until his death, but also to those whose loved one was infirm but remained alive. The carers anticipated that the dementia would eventually lead to death.

Carers of people with dementia also appear to experience symbolic loss in terms of hope for a safe future. Society may fail to appreciate the carer's anger and sadness, because illhealth in older people is accepted as more natural, unavoidable and not unjust in the way that it is viewed amongst younger people. Writers talk of the ways in which the person is removed from contact with the carer and how this can be a profound cause of feelings of loss. Wood notes that the person with Alzheimer's disease is no longer accessible or apparent, although still bodily present' (Woods, 1991:65). The comparison to a bereavement becomes appropriate both literally and symbolically. The carer watches their relative slipping away and knows that the path, though uneven on occasions, will be downwards ending in death. So long as the relative remains present, however, there is always hope, although remote, that some miracle may take place, and a recovery occur (perhaps a new drug will be discovered just in time). In this way, though some anticipatory grieving may be said to take place there can rarely be any move towards acceptance and reintegration, because the complete withdrawal of emotional investment is 'hampered' by the continued presence of the loved one. (Anticipatory grief has been used to describe the presence of depression and grief like symptoms during the terminal illness of a relative. It is thought to be associated with an easier adjustment (Fulton and Gottesman, 1980:47) after the actual death).

It could be argued that if bereavement theorists view the display of alarm, and searching as an essential mechanism linked to trying to retrieve the lost person (see Bowlby, 1986:87) then its role in the behaviour of carers becomes intelligible. As with those who have suffered loss through bereavement the carer's emotional and physical energy is given over to retrieving their relative and to soliciting the attention of others who might be able to help (we have read many accounts of carers' seemingly futile attempts to contact professionals). Although as time passes the prospect of 'bringing the person back', becomes more remote, it seems likely that the user's continued physical presence and the transient glimpses of their former self will keep the carer committed to maintaining their metaphorical 'search'. Gilliard has questioned the way that dementia has been portrayed as a 'living bereavement'. She observed that carers of people suffering dementia appeared locked into a cycle where they could not complete Kubler-Ross' stages of mourning successfully:

For many carers of people with dementia, when they are on the brink of acceptance, something happens which causes them to by-pass this stage and return to an earlier period. It may be that the carer's defences are lowered, perhaps through illness; or it may be that there is a 'window' in the sufferer's illness which allows a glimpse of their previous personality which was thought to be lost; or there may be a deterioration in the sufferer's condition which gives the carer a jolt, as if they have been knocked off the track and have to return to the start and get back on it again (Gilliard, 1992:18).

Professionals may be tempted to 'process' bereaved people through the stages and launch them forward towards new sources of emotional investment. In a resource-starved system evidence of outcome becomes essential. Carers of mentally ill people can not be made to grieve and let go to order. They are faced daily with a person who may show sufficient of their previous self to maintain hope, yet be affected by the mental health problem in a way that makes them inaccessible. The mentally ill person's state will often fluctuate, giving cruel glimpses of hope, and then crush them completely. How can the carer withdraw from someone who appears 'trapped' and is asking for help?

It is awkward to apply the loss model when the 'loss' is not tangible but subjectively defined. Brown and Harris, in their study of the causes of depression amongst women, successfully apply this concept (1984). They recognise that people relate to subjective interpretations of the world, and that as our unmaterialised hopes and expectations are very real to us their loss can have profound effects on our ability to function. If we are to apply loss theory profitably in the area of severe mental illness then this latter form of application would need to be adopted. The service user is likely to face the loss of more concrete features of life. These might include 'health' in its broadest sense, the opportunity to hold down a job, relationships may end as a direct consequence of the illness or one may be asked to give up driving. For the carer, especially a parent the loss is more likely to take a symbolic form. 'Unfortunately the illness often starts in adolescence or early adulthood, when the patient is at a critical stage in life and is expected to achieve most' (Kuipers et al, 1992:54). In other situations carers will be denied aspects of the relationship that had existed before the illness began. It will prevent the carer from relating to their relative as a full social, financial and emotional partner.

Evidence of the Stages of Grief in Carers of Mentally Ill People

The stages of shock, yearning and sadness, anger, despair, acceptance, and reinvestment cover almost the entire spectrum of human emotion, and it is therefore not surprising that one can identify the presence of at least some of these in relation to carers' experience. The difficulty in identifying a starting point for the caring process makes it almost impossible to compare individuals. Some carers recognised the full diagnosis through their son or daughter speaking a single phrase, but others took years to extrapolate from their relative's behaviour and compile evidence that supported the assertion that there was a mental health problem. Many women carers spoke of the initial phase of 'the early weeks where one cries and cries', (Mrs M). Mrs X said, "I never knew what or who might start me off crying". Another mother, Mrs Q, said that she had cried so much that she had never been able to cry again 'since I have nothing left'. This crying was often intense but gradually faded. Though the emotional pain was powerful it should not immediately be equated with the yearning for someone who has died. I believe that much of the crying might represent sheer distress, helplessness, and the expression of human suffering where help is sought from others. In the same sense that children will cry when they can no longer cope with a situation and in the way that those who have suffered a bereavement feel desolate and unable to bear their pain, so many carers feel almost intolerable anguish, especially in the early weeks, but this should not be confused with the yearning for someone who is lost.

There were feelings of great anxiety and alarm, amongst the carers, akin to those found in bereaved people, but these may be better understood as the reaction to crisis where one's usual coping mechanisms have become redundant. Some writers have chosen to view events such as divorce and redundancy as crises rather than as loss. Lascelles comments on crises which he suggests may *lead* to feelings of loss (1985:35). Parker also illustrates this idea cited by Smith, he sees bereavement as 'a loss of security which is perceived as threatening and produces a state of stress and alarm' (Smith, 1982:26). The features of the experiences described by the carers in the current study repeatedly emphasised trauma; perilous insecurity especially in relation to threats of aggression or suicide, the horror of the changes taking place in the relative and then, at times, the overwhelming sadness as one took stock of one's life. From this point of view it may be helpful to view the presence of the mental illness as creating a crisis. This crisis, if not resolved,

may lead to feelings of loss as familiar aspects of the carer's life are threatened or actually destroyed.

Bereavement theorists also talk about the anger which might be expressed towards the dead person and especially towards professionals. Collick records Mary Stott's comments 'rage creeps up on you unawares... as I walked along a crowded compartment and saw people laughing and talking and reading and sleeping, something in my mind went briefly out of gear. Their normality was hideous to me' (Collick, 1990:51). Carers of people with mental health problems may feel 'jealous'. They may envy the 'normality' of others, the nice holidays, cosy family Christmases, the successful son or daughter with their home and children, and even being able to sit in front of the television to quietly watch some nonsense. However, it would be insensitive to regard carers' anger at professionals as simply a 'stage' in a grieving process when it may indicate a real need to develop more sensitive practice. By framing the carer's emotions in a quasi-theoretical analysis professionals may insulate themselves from the depth of the feelings present and may miss important aspects of the assessment.

Numbness and shock were sometimes apparent. These responses were often linked to the provision of a diagnosis, especially if the term 'schizophrenia' was used. If carers were unaware that schizophrenia could frequently be a severe life-long illness, and were inadvertently given this message by professionals, they could be understandably daunted. The presence of depression amongst carers has also been well documented and commented on at an earlier stage in the thesis. Carers in the study might feel sad and utterly hopeless but then 'get up' to continue to support their relative. People spoke of consciously trying to keep some time for themselves. They might go out or go on holiday simply in order to survive, to keep on fighting, seeking help and diffusing suicide attempts so that they would still be there even if everyone else had deserted their relative. Although many people felt despondent at times, there was also a sense in which there was insufficient opportunity to be depressed, as the demands of caring often seemed relentless.

Carers and Attachment Violation

Although many carers suffered through the loss of aspects of their relationship with the relative, and were subject to the repeated effects of traumatic crises, one element of their experience remained particularly painful. This was the way in which their relative was not so much lost as changed. The experience is

not limited to bipolar disorder and schizophrenia, but appears associated with other forms of 'mental illness', whatever their alleged pathology. Although not observable amongst the small group of carers of people with dementia interviewed for the current study, many people affected by dementia do become hostile towards carers. Heywood explained that

the time of moderate dementia was probably the most difficult, for coupled with her increasingly irrational behaviour, Maria retained remnants of her adult authority. This combination often made it extremely difficult for me to cope on the practical level, and to endure her more unkind treatment of me (Heywood, 1994:213).

It was easier for him to cope as she became more confused, childlike and compliant. People with severe mental illness, however, rarely make fitting patients. Many carers in the current study were faced with the responsibility of watching over their relative and of increased domestic work, but any satisfaction that might have been obtained from knowing that their efforts were appreciated was often sabotaged by the changes in their relative. People were not lost as much as traumatically changed. Many carers in the current study were particularly distressed by the damage caused to their relationship with the service user. The data suggests that this aspect of the mental illness was a major source of the suffering for many carers.

Bowlby regards attachment behaviour as a fundamental human (and animal) activity. Connected to our survival it is 'conceived of as distinct from feeding behaviour and sexual behaviour, and of at least an equal significance in human life' (Bowlby, 1986:39). I believe that those close to people who develop mental illhealth have their attachment bond violated rather than broken. The carer is emotionally (and often physically) abused, as the person with whom they had a relationship speaks and behaves in a way that would once have been unimaginable. I am not suggesting that the relative was previously saintly but that the changes in them become central to the carer's unhappiness.

This experience threatens the carer's feelings of safety, challenges self esteem and shared hopes for the future as the relative pours scorn over their relationship. Data from the study suggest that often the carer's relationship with the user was the first or most prominent casualty in an episode. The process of attachment violation hits people deeply in areas of their life where

they had hoped for support and love. As Mrs CC explained, “we always told our children that they would be safe at home, that they would be loved. It didn’t matter what might happen to them outside, I never thought that the cause of suffering would come from inside our family”.

Some people changed, becoming permanently hostile towards their families, but others altered more intermittently. In both types of situation there were often vestiges of the relative’s original personality that remained accessible. These glimpses often proved very painful. They could be a source of hope that the person was still alive, buried beneath layers of illness, but also had the power to reawaken feelings of loss, helplessness, and desolation.

People with severe mental illness may not merely lose familiar characteristics but often may acquire traits which are the antithesis of their ‘old selves’. The person who loved you, who you could confide in, and whose opinion you trusted may become the one to accuse you of harming them, or may undermine everything that you do and say. Carers may face prolonged periods of hardship through the responsibilities of caring, which might be exacerbated by a form of ‘emotional abuse’. Perhaps this would be bearable after all, if carers can accept that their relative is ill, they may be able to forgive such cruelty. What appeared to be unforgiveable to many such carers was the inappropriate responses of professionals, who might accuse the carer of provoking the user by excessive emotional involvement, or even using the user as a scape goat for their own problems. This unfortunate form of misunderstanding appeared alarmingly common. (It could even be described as one of the experiences that marked a carer’s initiation into their role. I observed that it was something that carers recognised in each other and was often associated with a profound cynicism towards professionals).

Drawing on data from the current study my hypothesis is that the caring experience is commonly cyclical, marked by subtle changes in the user which are often imperceptible to professionals and to the user themselves. Given the emotional distress that many carers experience in relation to changes in their relative, such caring is better conceptualised as *attachment violation* rather than as loss. Can such a theoretical position be justified? The hallmark of good research is its ability to analyse, creating theory rather than description. Such theory should capture the flavour of experience, revealing dimensions previously inadequately articulated either by professionals or by the

participants themselves. Theory should be intelligible to professionals in the field, yet be recognisable to the people involved in the experience. The material from the current study has been validated by some of the subjects involved and with other carers in recognition of the commitment to a participatory approach.

During the interviews many people did not feel that they possessed adequate words to describe their experience. They indicated that it had been, and continued to be, very painful. I initially avoided 'feeding' carers expressions, but it became clear that some assistance was needed. This research process is mirrored in counselling theory through discussion on the role of empathy in counselling practice. Gendlin points to the ways in which the counsellor helps the client to reflect on feelings of which they may be aware, but are as yet unarticulated. These ideas are described as being at 'the edge of awareness' (Mearns and Thorne, 1988:46). It is a similar process that appears to occur in research. As a researcher I have not simply projected my own theoretical structure onto the experiences of subjects, but through a process of theoretical sensitivity (see Glaser and Strauss, 1968). I have attempted to reflect feelings, attitudes, and help name experiences that were on the 'edge of awareness'.

Women as carers

There appear to be some significant differences between men and women in the caring role, yet it was apparent from the General Household Survey of 1990 that the actual numbers of male and female carers are similar. Thirteen percent of men and seventeen percent of women said 'that they were looking after, or providing a regular service for, someone who was sick, elderly, or handicapped' (Office of Population Censuses and Surveys, 1990:1). It has been suggested by some writers that this figure may hide important features in the form of support provided. At the outset the current study did not focus particularly on differences relating to gender. However, in reviewing the data, it was apparent that many comments concerning the overpowering sadness experienced through the effects of mental illness in a relative had been made by women. Women, especially when acting as lone carers, were likely to make some statement about the emotional impact that their situation had had on them. This applied to those who lived with their relative and those who did not. (This is not to suggest that male carers were not affected by their experiences but it did seem that the women *expressed* more distress).

Given my gender and that men may feel less comfortable about admitting distress, it seems possible that male carers may have hidden their feelings or displaced them in some way. However, one husband caring for his wife, who had dementia, spoke very frankly about his sadness. Despite this finding I have been left with the belief that the apparent difference in the level of emotional distress is probably an actual reflection of the way in which women experience their caring role. Given the small scale of the study, and the limited data available concerning male carers, further work is needed to investigate this premise.

The observation that women may actually suffer in this respect is a source of concern. Feminist writers have drawn attention to the ways in which society has constructed 'the family' and 'caring' in a way that places responsibility on the shoulders of women. Dalley explains that women are expected to express their concern for others through the provisions of care. Where men are expected to 'care about' their family, women are also expected to 'care for' them. Indeed it may be viewed as 'deviant' for women to separate these two aspects (Dalley, 1988: 8). Dalley suggests that the family, and its acceptance as the natural vehicle for providing support, creates the ideological basis that entraps women in caring roles. She also recognises the ways in which many women have internalised the requirement to care and even come to regard it as part of their nature (Dalley, 1988: 17). This latter observation was apparent in the current study, where carers spoke of their 'right to care' and of the 'pride' experienced in supporting someone to the best of their ability. While I would not wish to challenge the choice made by such women one is able to recognise the ways in which women are socialised into this position. Nor does the fact that carers actively choose to care justify society in leaving carers unsupported in their role.

Given that women may define themselves through caring, the frustration and distress that carers of people with mental health problems face may feel particularly painful. Lewis and Meredith note that Gilligan has stated that

'the feminine personality comes to define itself in relation to and in connection with others more than does the masculine personality, which is defined primarily through separation. In this construction, concern for others rather than self - an ethic of care - becomes central to the understanding of femininity' (Lewis and Meredith, 1988:5).

Carers in the current study found the deterioration in their relationship with their relative very difficult to cope with. Given the above comments about how women define their identities, it does not seem surprising that this was the case. Mrs X and Mrs O both felt, despite knowing that their sons were mentally ill, that it was difficult not to accept blame when their sons accused them of causing the 'symptoms'.

The problems experienced by women in the caring role may build on other experiences in an unfortunate way. In a study of domestic violence Dutton explains that, because a significant percentage of women experience child sexual abuse, violence and / or emotional and psychological abuse in partnerships will represent a repeated rather than initial exposure to abuse (Dutton, 1992:9). In some of the more extreme cases in the current study it can be argued that the relationship between the carer and their relative may be characterised by features that elsewhere would be regarded as constituting abuse. The effects on the 'carer' may be similar: anxiety, low self esteem, isolation, and depression. Some of the damage caused in this way could be alleviated by professionals. It can be suggested that the relative is not 'themselves', that they are not intentionally harming their family, and that they too are often very afraid. Sadly, 'abuse' experienced by carers may be compounded by the accusations of professionals suggesting that carers are being 'over sensitive', and at worst are actually to blame for the mental health problem. Women, mothers in particular, appear to be vulnerable to such comments which may find root in their low self esteem.

Recognising need and developing practice

An enduring problem raised in this study (and elsewhere) concerns the ways in which mental illness is both conceived and responded to in western industrial society. Mental illness is linked to other phenomena which may differ significantly, for example so called physical disabilities. Those who view schizophrenia as a brain disorder have, as yet, failed to convince many professionals because of the apparently large non-genetic component present in its transmission. There is also the suspicion that abnormalities of neurotransmitter levels, which are believed to be associated with schizophrenia and depression, are as much effects of social and psychological processes as they are causes of mental disorder.

Those who advocate the non-existence of mental illness, in particular the form where the sufferer requires someone else to tell them that they are 'ill', also fail to convince. The debate has been associated with a sterile feud between so-called social and medical models of mental health. The medical model protagonists are like paramedics who treat the injuries of a person lying in the road but are unwilling to discuss the patient's concern over the drunk driver who knocked them down. The social theorists are preoccupied with the need for better traffic laws but seem unable to respond to the patient's broken leg.

While opposing camps debate the epistemological status of mental illhealth people confronted with these problems need strategies to help them live. Severe mental illness can be understood as having *similarities* and *differences* from other problems. Data from the current study suggest that carers believed that mental illness was something real, powerful, and at times had the semblance of a being in its own right. It can appear and to all attempts and purposes be present in people despite their lack of insight, however, carers are often not assisted in coping, because they are told that, since other problems do not manifest themselves in this way, there can be no mechanisms for responding to them.

We need to move forward, accepting the existential reality of the problems faced by users, carers, professionals and by society in relation to so called severe mental illness. Any response that ignores the needs of one or more groups will prove both unjust and unworkable. It is only comparatively recently that users of mental health services have been offered choices and a voice to comment on the the services that they receive. Many might still argue that the balance of power is overwhelmingly loaded against them. However, a requirement to consult users in connection with strategy and their personal care planning is now firmly embedded in the system (for example the involvement of users in the Care Programme Approach). If one recognises the part played by carers in the provision of care, support, and in relapse recognition, a need for appropriate involvement of carers becomes both ethical and sound. Although the structures for such involvement have been growing, through the development of the Care Programme Approach, implemented in 1993 (See Carpenter and Sbaraini, 1996), and through the Carers' (Services and Recognition) Act 1995, the current study did not demonstrate that carers were meaningfully involved in care planning or provided with adequate information and assistance. Although the study fieldwork was completed before

the implementation of the Carers' (Services and Recognition) Act in April 1996, current contact with carers in the study (1997) has not indicated that this legislation has led to any significant change, in their opinion. They appeared cynical, especially as resources appeared to be increasingly limited, viewing carers' needs as being a low priority in the eyes of Health and Social Services.

There are a number of issues that appeared to require a change in practice. The process where information on the nature and prognosis of the mental health problem was provided appeared haphazard. Where a carer is intending to provide significant support to a user such information is required to assist the carer in offering effective support and in coping with any crises. Changes in the professional team might lead to a situation where no one possessed a clear sense of responsibility about providing such information and keeping it updated. Ironically, users with more severe problems might be less willing for such information to be shared with their carer because they do not accept that they had a mental illness. However, given the spate of tragedies, and the responsibilities faced by carers through the retraction of state institutional care, guidelines are needed to permit some sharing of information and provision of details of where to seek help in an emergency. These standards require ongoing monitoring and evaluation.

Many families in the current study were alarmed that they were apparently unable to make professionals respond to requests for help. There are obviously problems in this respect, and it would be a dangerous infringement of the rights of patients if one's relative possessed the power to label one as insane. However, the current study suggested that the balance might be weighted towards the other direction, and consequently, where users were denied help, one might argue paradoxically, that they still suffered a violation of their rights. Some procedure could be developed where referrals could be made by non-professionals, eg a carer, with regard to the mental health of individuals, and received without prejudice by the GP or Psychiatrist. In any case concerns expressed by carers about the mental health of a relative should be received in a sensitive way, *regardless* of whether the professional feels intervention is appropriate. A re-examination of the principles of confidentiality and autonomy would be appropriate in professional training courses. Such referrals might be logged by Health and Social Services with access permitted only to the authorities.

Once a user has been accepted into the Care Programme Approach it could be helpful to formally nominate one family member or friend as the designated 'Carer'. Fully involved in the care planning process, this Carer would also have the authority to take their concerns about the user to the key worker, GP, or consultant. This procedure would recognise the sensitivity of the Carer to changes in the user and is the same right currently afforded to other members of the care team. This would clarify medical concerns over confidentiality which have frustrated carers in the past, but would not bind professionals to act on such concerns. In most cases it would be expected that users would support this arrangement. Where they did not then a carer could only be nominated where that carer provided significant support, and there was concern over self harm, violence, or self neglect.

Apparently, in China, decisions about mental illness where the 'user' does not acknowledge its presence are made by family and local committee members. These are lay people who live, work, and socialise with the individual and would therefore be potentially sensitive to changes in behaviour, mood, or thinking. The involvement of the 'community' is apparently accepted, whereas in western industrial societies such matters are regarded as very private. In contrast Dalley (1988) recognises contemporary western industrial society's adherence to 'familism'. The support of members is regarded as the responsibility of the immediate nuclear family and the state has a duty care only when the family has broken down and can no longer fulfill its obligations. Dalley adds (Dalley, 1988) that within the nuclear family the burden of care is frequently placed on women. While data from the current study suggests that many carers did want to support their relative, carers often appeared strained by the responsibility of caring in isolation from others, and without adequate formal or informal support. If caring could actually become the responsibility of the local community then breakdown in supportive relationships might be less likely.

Judgments made about the need for intervention against a user's wishes should never become the burden of carers alone. Unfortunately, where contact with professionals is sparse such judgments may come to depend heavily on the opinions of carers or may be avoided completely, because of a fear of the carer's subjectivity, leading to prolonged suffering. There is a need for information to be drawn from other people in regular contact with the user

which would permit decisions to be made on a sound basis. Difficult decisions such as those made in relation to child protection issues are best made by a pooling of the resources, and the sharing of differing but complementary perspectives, rather than by any one individual.

Citizen advocates are increasingly developing close and enduring relationships with mentally ill people. However, it would be inappropriate to expect advocates to comment on aspects of the user's mental health that they might not acknowledge, as this could endanger the trust that the user is able to place in this relationship. It has been suggested that carers should also have advocates (in order to redress the balance of power between the user and themselves). This may only further threaten the user's already fragile sense of privacy. Rather than re-emphasise the boundaries between the family and those outside it might be more rewarding to strengthen and encourage the development of more ties with the wider community. Part of the pressure that such families experience may derive from the ever-growing sense of isolation and stigma that many in the current study experienced.

It could be argued that communities do not actually exist in a way that would permit members to exercise functions of support and control over mentally ill people. Given the apparent extent of fear and prejudice, there would be a need for widespread education to breakdown the barrier of fear that currently exists. This hope appears idyllic at present, but only then might there be a chance to draw mentally ill people and their carers back into the community. Society may realise that schizophrenic people need not be ostracised, but may have something positive to offer it. Until then, carers will be forced to fight a lonely battle, maybe with only themselves to turn to for aid when it is needed most.

Appendix One

description of respondents

Mrs A

Supports her daughter who has been diagnosed as suffering with schizophrenia. In addition to being involved with the study I visited the family as their social worker following her discharge from hospital between 1991 and 1993. When I last visited the family her daughter had kept well for some time and enjoyed a range of interests. Her daughter is in her thirties and lives at home. Neither mother nor daughter work and Mr A spends long periods working abroad. The daughter has been in hospital on three occasions. She was regularly supported by myself, a community nurse and psychiatrist .

Mrs B

Is a widow in her seventies who lives alone. Her sister had the house next door until she committed suicide some weeks before I interviewed Mrs B. The sister had suffered with bipolar disorder since she first had her children. She had many admissions to hospital for ECT but the problem seemed to become harder to treat as she grew older. I had a short involvement with Mrs B's sister prior to her death and then visited Mrs B for around six months in 1992 .

Mr C

Had cared for his wife during the months that she suffered from very severe depression and what was called a 'psychotic illness'. She had had a number of admissions to hospital but

seemed slow to recover. This meant that he needed to support her when she was at home and look after their two children. My initial involvement was as a social worker to Mr C's wife but I continued to visit him regularly between 1991 and 1993.

Mr and Mrs D

Are a retired couple who support their daughter. She had to give up her job when she first became ill in the mid eighties and has been unable to work since that time. She spends her days at home with her mother and father. Although she takes her medication she still suffers from unpleasant thoughts and is often very tired and depressed. I became her social worker in 1990 and at the family's request still visit her. At present (1997) I see Mr and Mrs D and their daughter about every six weeks. I would consider my role to be that of a befriender. Since discharge from hospital in 1990 she has had several changes of psychiatrist and many changes of community nurse.

Mrs E

Supported her son who lived at home and worked in the family business, until her death a few years ago. Her son was single and had had several admissions to hospital and was eventually described as having schizophrenia. Despite medication he was often tired, depressed and wished that he had enough energy to be able to work again.

Mrs F

Supported her husband who developed a an early onset dementia in his forties. She lives in an urban area in the north of the study region. She cared for her husband until his death ten years later. Mrs F currently works in the care field and was referred through a contact at the university. I met Mrs F on one occasion when I interviewed her for the study in 1992.

Mrs G

Supported her mother who lived a few miles away and subsequently went into residential care. Her mother was diagnosed with Alzheimer's disease and was referred to the study by the psychogeriatrician. Mrs G is married and has adult children of her own. I met Mrs G on one occasion in 1992 when I interviewed her for the study.

Mrs H

Supported her brother who lived close by until his dementia led to his admission to residential care. She is married and now supports her husband who is retired and in poor health. Mrs H would have liked to have cared for her brother in her own home and resented the fact that her husband would not allow this. I met her on the one occasion when I interviewed her in 1992.

Mr I

Is an older man who supported his wife who developed dementia and was eventually

admitted to a long stay hospital ward. He lives alone and misses her a great deal.

I met this man on the one occasion that I interviewed him in 1992.

Mrs J

Is a woman who was personally known to me as a colleague. She offered to be formally interviewed in 1992 so that I could contrast the experience of caring for someone with a learning disability. She described how she became a 'carer' a few days after her son was born and was diagnosed with Downs Syndrome. He was rejected by his father and she feels that she has fought on her son's behalf ever since. He is now a young adult.

Mrs K

Learned of the study through a mutual acquaintance and referred herself. I met her on the occasion of the interview in 1993. She 'grew up with schizophrenia' and her mother's many periods in hospital. Her father was the main carer but left and remarried. She felt that he always remained guilty about this decision. She is married and works full time in a professional job but continues to support her mother who lives a few miles away. She explained that she will not allow her mother to encroach on her life but provides support within a strictly defined format.

Mrs L

Works full time, has a family and periodically supports her sister and her sister's children who live a few miles away. Her sister has been

in and out of hospital for twenty years but does experience some 'good patches' in between. When her sister is ill Mrs L finds that her sister becomes resentful and angry towards her making the task of caring very difficult. I supported her sister during a number of admissions to hospital and during her recovery from 1991 to 1994. I met with Mrs L from time to time, usually during crises or at review meetings. I made two formal interviews with Mrs L during 1993. The data was recorded at a time when Mrs L's sister was well.

Mrs M

Supports her brother (aged in his forties) who lives in hospital for most of the week but comes to stay with her family two days per week. Her brother has had a long illness that has responded poorly to drugs. He was initially cared for by their mother but she now has dementia and also depends on Mrs M for help. Mrs M runs a local carers support group and works part time in between caring.

The interview tape was made in 1993 but I also visited her support group on around six occasions and have met with Mrs M 2-3 times per year at her home. Living in the same area we have a mutual interest in the problems encountered by local carers and their families. I continue to see Mrs M, time permitting (1997) and she occasionally contacts me for information about services, carers' rights and medication.

Mrs N

Is a home maker who is married and supports her son. He is in his early twenties and has had two episodes of schizophrenia. He lives at home at present but it is hoped that he may recover sufficiently to return to college.

I supported Mrs N and her son from 1993-4 as their social worker. I visited the family regularly meeting both Mrs N and her son together and independently. I do not know how they are currently keeping .

Mrs O

Is divorced and lives alone. She also suffered with mental health problems and has found her son's illness difficult. She both wants him to be able to live with her but finds the responsibility difficult especially when he is suicidal. I made the interview tape in 1993 during a difficult time, when Mrs O was supporting her son in her home, after the break up of his marriage and subsequent suicide attempt. I visited Mrs O regularly, but as a social worker my focus moved with her son, when he made a new relationship and moved to his own home once again. I ceased to have contact with her son on moving jobs in 1994. I understand that he has continued to experience difficulties with his mental health.

Mrs P

Has stayed at home for some years to care for her son who has schizophrenia. Her husband works and shares the care when he can. Mrs P is rarely able to leave her son unattended. He

reacted very badly to medication some years ago and therefore the illness has been left untreated. His family did not feel able to leave him in hospital and made the difficult decision to care for him in their own home.

I met Mrs P at a support group and interviewed her at their home in 1993. Though I have not seen her recently (1997) another carer provides contact. Mrs P has had difficulties recently in connection with attempts to find suitable medication for her son. She remains responsible for him in the community and depends on her husband for support. Mr and Mrs P are getting older and her husband is ill at present. They have been provided with a care attendant twice weekly.

Mrs Q

Supports her son who lives independently but is often verbally and physically abusive. Statutory support is ineffective because he is unwilling to keep appointments on a regular basis. Mrs Q's husband and adult children are unhappy about her commitment to her son in view of his behaviour. I met Mrs Q for the interview in 1994 but other carers in her support group have told me (1997) that their situation continues to be very difficult.

Mr R

Is a retired man who supports his daughter who suffers with schizophrenia. She continues to experience some problems and needs hospital care at times but is largely able to cope. He says that she has always been happy to accept

treatment and appears to do well on this. It is now some years since there have been any crises. I met Mr R at a support group in 1994 and have not had any contact since that time.

Mr and Mrs S

Are a retired couple who support their son who has schizophrenia. They are in regular contact with him but he has stayed well on his medication and lives in a supported residential project for people with mental health problems. Mr and Mrs S seem to be able to get on with their lives and their son is currently (1997) studying at college. This is not at the academic level that he would have attempted prior to his illness but it appears to be satisfying. I meet Mr S regularly at meetings in connection with mental health issues.

Mrs T

Supports her cousin who suffers schizophrenia. He has no close family left alive and she has stepped in to provide support since his father died. Contact is regular but he lives independently. Support involves hospital visits, assistance with budgeting and maintaining his home. She works full time and has her own partner and children. I met her at a support group and interviewed her at their home in 1994. This is the only contact that I have had with Mrs T.

Mrs U

Lives with her second husband and supports her son who is in his early twenties and suffers with what has been called unipolar mania. He lives at home and appears to be gradually recovering. Mrs U found her son's illness and hospital admission traumatic and felt that it had put pressure on her marriage. She responded to a request by the carers' counsellor for research subjects and I met her for the interview on one occasion in 1994.

Mrs V

Supports her daughter who has had one traumatic admission to hospital but has had no other treatment. Mrs V sees herself as the main carer as her husband is usually at work and her daughter's episodes of verbal and physical aggression are usually targeted at her mother. The family are torn apart by the distress of their daughter's problem and the apparent lack of any help. From their descriptions their daughter suffers auditory and visual hallucinations consistent with a diagnosis of schizophrenia. Contacted through the carers' counsellor I met the family on one occasion in 1994.

Mrs W

Supported her son who suffered from schizophrenia until he committed suicide a few months after our interview. He had experienced severe difficulties for some years and though his mother and father lived separately from him, his illness strongly influenced the way that they

were able to lead their lives. Some years before his death he had set fire to his parents' home. I met Mrs W through the carers' counsellor on one occasion in Summer 1994. I learned of her son's suicide (in October that year), through another carer.

Mrs X

This woman supports her son who was diagnosed with schizophrenia when he was at university. He spends almost all of his time in hospital, usually on a section of the Mental Health Act 1983. He recovers sufficiently to be given leave but invariably deteriorates and has to be readmitted. His mother is now retired and lives alone. She spends a significant part of every week visiting him and helping him manage in his own home when he is out of hospital. I met Mrs X after contact through the carers' counsellor in 1994. Since that time I have got to know her well through our work with a voluntary agency. In 1997 her son remains in hospital under the Mental Health Act. He has not improved or responded to treatment sufficiently to allow him to live in the community.

Mr and Mrs Y

Support their son who suffers from schizophrenia. He is separated from his wife and children who live in another part of the country. Mr and Mrs Y are retired and try to help their son who lives independently, especially with bills and in claiming benefits. This is often quite difficult as he is not always

amenable to such support. I met the family on one occasion following referral through the carers' counsellor in 1994.

Mrs Z

Is an older woman who lives alone. Her son who is diagnosed with schizophrenia was living in hospital when I visited. Occasionally he runs away and hides in her house because he feels that he is being followed by people who want to harm him. Mrs Z appeared upset and confused by her son's problems and appeared to have very little support of any kind. Mrs Z contacted me through the carers' counsellor and I met her on one occasion in 1994.

Mrs AA

Is a married woman with young children. She supports her mother who has suffered with schizophrenia for many years. Both she and her father (who divorced her mother) visit her mother regularly and contact the services when they feel she is at risk. I met Mrs AA on one occasion following contact through the carers' counsellor in 1994.

Mr and Mrs BB

Are a retired couple who care for their two sons. One suffers with schizophrenia and lives with them all the time, the second has a learning disability and comes to stay during the holidays. It is difficult to care for the two together as the illness causes the son with schizophrenia to be particularly inflexible at times. I interviewed the family in 1994 after

contact through the carers' counsellor but meet Mr BB at voluntary organisation meetings. In 1997 their situation has altered very little.

Mrs CC

Is a mature student and home maker. She lives with her adult son and she has recently become divorced. Some three years ago her husband of almost thirty years developed what she believed to be a psychotic illness and eventually left her. She made repeated attempts to obtain treatment for him but he denied the problem and the professionals felt that there were insufficient grounds for a statutory admission. I met Mrs CC through the carers' counsellor in 1994. She contacted me soon after the interview to ask for support. Since that time I have assisted her in connection with her husband's mental health problems and in obtaining a separation. We found that we had much in common and continue to meet as friends (1997). Mrs CC took an active role in discussing the themes that arose in the study and in reading the draft.

Mrs DD

Is divorced and works full time. She supports her son who suffers from schizophrenia. As they live in a relatively isolated rural area visiting hospitals for inpatient and outpatient care has proved difficult. His illness also feels very visible to her in their village. I met Mrs DD on one occasion through the carers'

counsellor in 1994. She lives some distance from my home and I have not had any contact or news of her since that time.

Mrs EE

Had experienced schizophrenia in her mother but is now supporting one of her sons who has been recently diagnosed. She lives with her other two sons and partner but feels that the real responsibility lies on her shoulders . She maintains a sense of humour about the illness but explains that it is only a means of warding off the desperation. I met Mrs EE through the carers' counsellor on one occasion in 1994.

name and age group	gender, SEG	referral route	diagnosis of user	relationship to user
Mrs A,50s	F, WC	referred to social work after admission to psychiatric hospital	schizophr-enia	mother
Mrs B,70s	F, WC	social work	bipolar	sister
Mr C,40s	m, WC	social work	affective psychosis	partner
Mr, Mrs D,70s	F & M, WC	social work	schiz.	parents
Mrs E,70s	F, MC	social work	schiz.	mother
Mrs F,50s	F, WC	university	dementia	partner
Mrs G,40s	F, MC	psycho geriatrician	dementia	daughter
Mr H,60s	F, MC	psycho geriatrician	dementia	sister
Mr I,70s	M, WC	psycho geriatrician	dementia	partner
Mrs J,40s	F, MC	university	downs syndrome	mother
Mrs K,40s	F, MC	university	schiz.	daughter
Mrs L,40s	F, MC	social work	bipolar	sister
Mrs M,40s	F, WC	self help group no.1	schiz.	sister
Mrs N,50s	F, MC	social work	schiz.	mother
Mrs O,50s	F, WC	social work	bipolar	mother
Mrs P,50s	F, WC	self help group no. 1	schiz	mother
Mrs Q,60s	F, MC	self help group no 2	schiz	mother
Mr R,60s	M, MC	self help group no. 2	schiz	father
Mr, Mrs S,60s	M & F, MC	self help group no. 2	schiz	parents
Mrs T,50s	F, MC	self help group no. 2	schiz	cousin
Mrs U,50s	F, MC	carers' counsellor	unipolar mania	mother
Mr, Mrs V,50s	M & F, WC	carers' counsellor	none	parents

Mrs W,50s	F, MC	carers' counsellor	schiz.	mother
Mrs X,50s	F, MC	carers' counsellor	schiz.	mother
Mr, Mrs Y,70s	M & F, MC	carers' counsellor	schiz.	parents
Mrs Z,70s	F, WC	carers' counsellor	schiz.	mother
Mrs AA,30s	F, MC	carers' counsellor	schiz.	daughter
Mr, Mrs BB,70s	M & F, MC	carers' counsellor	schiz.	parents
Mrs CC,40s	F, WC	carers' counsellor	none	partner
Mrs DD,50s	F, WC	carers' counsellor	schiz.	mother
Mrs EE,50s	F, MC	carers' counsellor	schiz.	mother

appendix two, a description of the research process and analysis

In early 1991 I began to consider possible topics for a piece of indepth research. During my work as an Approved Social Worker (this is a social worker empowered to detain people for compulsory treatment under the Mental Health Act 1983), I came into contact with many people suffering from severe mental health problems and with their families. Working with one such family I became interested in the idea that the experience of families could be understood in terms of *loss*. Rather than using this as a hypothesis I made the decision to use this idea as a starting point to guide the exploration of an area of study. Having registered as a part time Ph.D student with the Centre for Applied Social Studies at Durham University in October 1991 I sought permission from the local research ethics committee and from Social Services. I was required to present my proposal to the committee and was given approval in December 1991. At that time Social Services lacked any formal mechanism to respond to requests to conduct research.

Guided by the university, and by a recognition of the limited resources that were at my disposal, I decided to interview around thirty respondents. A decision was made to adopt a qualitative approach and to analyse data at regular intervals. It was felt that qualitative methodology would be appropriate in a situation where the study sought to explore and understand experience, especially in reflecting the ways in which subjects themselves constructed their world. Qualitative methodology would also allow the study to be flexible to developing themes.

The process could be described as a spiral with periods of interviewing, coding, analysis and theory building, leading to further material for subsequent interviewing. Five carers were interviewed initially and then the implications applied to inform work with the next group of subjects. Latterly carers were chosen to allow the study to explore particular themes and to assist in achieving saturation. (This process reflected the concept of theoretical sampling (Strauss and Corbin, 1990) where cases are sought for their impact on the developing theory). I believe that any claim to have covered the full spectrum of variables must be tenuous as it is impossible to be conscious of all possible sources of diversity. Given these conceptual limitations I made every effort to select carers who reflected a broad range of circumstances. I also attempted to 'loosen' my existing conceptual framework and sensitise myself to the ways in which carers themselves constructed their experiences.

The interviews were conducted with a semi structured format that permitted me to respond to themes considered pertinent by the subjects, yet which allowed me to maintain some direction that reflected my own priorities. In this way the study attempted to maintain a balance between my priorities and interests and those of the subjects. A list of question areas was drawn up for this purpose (see list later in this appendix).

Subjects were approached and offered an explanation about the content of the interviews and purpose of the study. I explained that I hoped to reflect their experiences and to influence professional practice, but added that I had little actual power to effect change. Subjects were told that their material

would be presented in a thesis and possibly in other material, but that their individual details would remain confidential.

I visited people in their own home, given the caring responsibilities of some subjects this felt essential. I could not insist on the the carer being interviewed alone and readily included the user or other members of the family if they wished this. Most, but not all, of the interviews were taped as I always respected the subject's wishes in this area. In addition hand written notes were used to supplement the tape recording. The tapes were subsequently played through by myself and used as the basis for making a condensed record of the interview. Respondents were able to view these transcripts. This allowed people to alter comments if they felt that the stress of their words had been misinterpreted. Some pertinent discussion often occurred when we talked freely after the tape recorder had been switched off. It is my intention to destroy the tapes some six months after the thesis has been examined.

Only one person was 'out' when I called to interview them. I took this to represent a refusal and did not attempt to pursue this further. As I have explained in the text I was aware of how easy it was to encourage people to talk and my subsequent status as a carer only added to my apparent credibility. This meant that the responsibility to respect the dignity and privacy of everyone involved was mine alone. Each subject was given written details of the aims of the study, a contact address, details of where to make a complaint and were asked to sign a consent form. Interviewees were also told that they could ignore questions that they felt uncomfortable about, or stop the interview, and withdraw consent at any time. No one asked to do this but I did use my professional skills in a quasi therapeutic

sense where people became upset, or when they asked for information about connected issues. Where appropriate I contacted other agencies on the subject's behalf. If they requested services, information or help in the longer term, I recognised that this could not usually be offered by myself after the research interview was concluded.

In order to secure a sample that reflected the range of differing characteristics, that might have affected subjects' experiences, I sought a varied group of respondents. This reflected variables that my professional (and latterly personal) experience suggested might be pertinent. For example, the carers in the sample are drawn from a variety of age groups, social backgrounds, locations within the geographical area of the study (ie urban and rural), relationships to the service user and point in their 'caring career'. The group shown as 'social work and post discharge' referrals were people *in the mental health system* . These carers supported family members who had been in hospital and had received treatment for a diagnosed severe mental health problem. They had a named psychiatrist and often a key worker who might be a Community Psychiatric Nurse or a Social Worker / Care Manager. In order to reach carers whose relatives might be unwilling to allow a family member to talk about their experiences I later sought subjects directly through the carers' worker of a mental health voluntary organisation. In this way I was not constrained by the requirements of the Research Ethics Committee, regarding the patient's consent, and was also able to talk to carers across a wider geographical area. I recognised through professional experience that some users allegedly lack insight into their mental health problem and might resent their 'carer' discussing the situation.

In order to explore the theme of 'loss' in the experience of caring for someone with a severe mental illness I also chose to talk to four carers of people with a dementia. Literature in the main body of the thesis discusses how the presence of dementia may be seen as leading to a situation where someone is *lost* to their family (though not actually physically dead). It was hoped that a comparison might lead to a clearer recognition of the characteristics of the main study group (carers of people with schizophrenia and bipolar disorder). As the people suffering dementia, could not offer their consent to my approaching their carer, I sought the permission of their psychiatrist.

The formal interviews were carried out during 1992, 1993 and 1994, though as detailed in the list of respondents, there was more extensive contact with some subjects. Indeed as my own caring status emerged some of the respondents became part of my own support network as a carer.

Analysis could not be carried out with computer software as I did not have access to a personal computer until september 1996 (one month prior to submission). Word processing was carried out by secretarial staff at my college and at the hospital where I had worked between 1991 and 1994.

In conducting the analysis I sought emerging themes from the data. These have been described by Dey as 'patterns or regularities' (Dey,1993: 47). Perhaps the most important tool in the analysis was the ability to 'question', and where I located patterns I also searched for exceptions, asking what might have made a difference. As Dey explains 'where we find regularities, we can also find variations and exceptions' (1993: 47). In human experience the range of possible 'causes' or explanations are always seemingly infinite but

this did not make the search for some common themes, or the construction of an account a pointless exercise.

Personal material provided an enriched dimension to the data that I was able to access. Rather than reflecting a 'snap shot', as did the single interviews, it offered the opportunity to explore the experience of caring through each day. Having accepted Glaser and Strauss' (1968) suggestion that the researcher keep notes concerning the emerging theory, problems and issues, I found that the requirement to maintain a reflexive awareness meant that I had actually stumbled on the caring experience being constructed in my own life. While my experiences were an isolated case, they provided a depth of experience that enabled me to relate to aspects of the carer's encounter with the system that go unrecognised by professionals. An analysis of the respondents' material in isolation from my 'personal caring diary' supports the study's findings and my personal experience would not appear to be particularly unusual. A decision was made on ethical grounds not to seek to recruit carers in crisis, and to interview them at that point, therefore carers often found it difficult to recall some of the intensity of experience that is apparent in my personal material. A small number of carers have reviewed the whole draft thesis. In accordance with the commitment to participatory methodology I wished to maintain an emphasis on making their voice audible. Given the opportunity to examine the draft thesis carers did unhesitatingly endorse the contents and the inclusion of my own personal material.

Themes did emerge. I came to hear familiar stories. The carers were individuals from very different circumstances, but there were sufficient similarities in the accounts that they offered to permit the construction of a theoretical account, one that attempts to present the experience of a group of people.

format for semi structured interviews

The initial list of question areas or topics was drawn up in 1991. It represents my own conception of what issues I considered might be relevant at that time. These question topics were modified after initial data began to inform the study design. The following list was used from 1992 onwards. However I always gave carers the opportunity to include additional material in the discussion and allowed the conversation to follow any issues broadly relevant that appeared important to the respondent. I came to observe that one often had to adopt direct questions concerning themes such as 'loss'. At times, by attempting to be impartial and not prompting the subjects, they might simply omit commenting on something that appeared so obvious to them, as to be unworthy of inclusion. Hence later interviews were often more focussed with specific questions around emerging themes such as the illness' impact on the carer-user relationship and any involvement with professionals.

question topics

1. Details of the carer's age, gender, SEG, other family members, living circumstances, their relationship to the user, the duration of their caring responsibilities. Awareness of caring identity (if any). Eg. are they caring for, or supporting others, if so what does this involve?
2. Without prompting or suggesting a diagnosis, description of service user's illness. What does the carer call the 'illness'? In what terms is it understood? How did it first develop? What made the carer feel that there was something 'wrong'. Probe, had they ever seen anything like this before?
3. How and why did they first seek help? Who was this from? Friends,

family ,GP? Did the police become involved? How did the carer feel about 'getting help'? What was the user's attitude to this? What kind of response did the user or carer receive when they sought help? Probe for positive and negative responses.

4. What happened during this time? How did the user behave, think, feel? How did the carer feel at that time? Were there any particular occasions that the carer can recall? Probe for self harm, aggression, distress?

5. Did the user have to go into hospital/ residential care? What sort of help did the user receive during this time? What were things like at home? What were things like when the user came out of hospital. Where did the user go to stay when they left hospital? What forms of support did the user get? What sort of help did the carer receive?

6. How have things been since that time? Probe for repeated admissions or recovery. Does the user have to take any medication? Probe for side effects, compliance, carer's feelings about this.

7. What impact if any, has offering support had on the carer's health? Now and in the past?

8. What kind of support if any, do the user and carer currently receive. Probe for strengths and problems. CPN, SW, psychiatrist, GP, support worker, day care, supported housing, self help group, carers' counsellor, family, friends. Can you suggest any ways in which things might be improved?

7. How are things at present? What sort of things (if any) does the carer have to do for the user? Probe, prompting with self care, cooking, finances, self harm, intimate care, medication, 'keeping an eye on'.

8. Some people say that having someone close suffer with mental illness is like losing someone, what are your feelings about this?

9. Are there any things that you would like to tell me about that might help improve the support received by people with severe mental health problems and their families? Are there any other aspects of your experience that you would like to discuss?

thesis concept emerges from
personal social work practice
supporting adults with severe mental illness
as 'loss' (1991)
registration for Ph.D part time (1991)

approval from local research ethics committee (1991)

referral sources

local social work / multi	self help groups:
disciplinary mental	one and two
health team	
	carers' counsellor
others	psychogeriatrician

list of questions for semi structured interviews

	1991-1996
interviews, taped	fieldwork and
with hand written notes	<i>personal caring diary</i>
(1992, 1993, 1994)	

condensed transcripts made from tape
and notes
(1992-1995)
hard copy approved by subject

analysis 1992-6

**search for themes eg. 'professional deafness',
'scenes', 'amateur doctor', 'being out', 'information',
'more than the brain can take'**

emerging themes used to inform further interviews

**draft account read by small number of carers from study
1996**

**thesis account
1996-7**

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